

MEN'S SELF-PERCEPTIONS OF MASCULINITY IN
RESPONSE TO ACQUIRED ILLNESS OR INJURY AND
SUBSEQUENT CHANGES IN OCCUPATIONAL ROLES

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Table of Contents

List of Tables	vi
List of Figures.....	vii
Acknowledgements	viii
Abstract.....	ix
Chapter One – Introduction and Background to Study	1
Background.....	3
Occupation.....	3
Occupational roles.	4
Masculinity	5
Masculinity in New Zealand	7
Men’s Health and Disability Profile.....	8
Health and Disability in the New Zealand Context.....	9
Health and disability system.....	9
Accident Compensation Corporation.	10
Work and Income New Zealand.....	11
My Interest.....	11
Summary.....	13
Chapter 2 - Literature Review	14
Method.....	14
Results	15
The male body.	15
Sport and disability.....	18
Virility and sexual function.	21
Inability to protect and financially provide.	24
Fathering and the domestic sphere	26

Avoidance and help seeking	27
Control, vulnerability and loss	29
Renegotiating masculinity.	31
Summary.....	33
Chapter 3 - Methodology and Methods.....	35
Methodology.....	36
Why qualitative research?	36
Why a qualitative descriptive design?	37
Which paradigm?.....	39
Ontology.	40
Epistemology.....	40
Summary.....	40
Methods	41
Ethical considerations.....	41
Research sample.	42
Sampling.....	42
Inclusion and exclusion criteria.....	43
Participant recruitment.	44
Data collection.....	46
Semi-structured interviews.....	46
Confidentiality.....	50
Data analysis.....	51
Preparation.....	51
Analysis.	52
Reporting.	54
Issues of trustworthiness.....	54
Summary.....	56

Chapter 4 - Findings	57
Demographic Data.....	57
Employment.	58
Before injury/ illness.	58
After injury/ illness.....	59
Leisure.	59
Before injury/ illness.	59
After injury/ illness.....	60
Family.....	60
Before injury/ illness.	60
After injury/ illness.....	61
What Does It Mean To Be A Man? – Thinking Back To Before Illness/ Injury	61
Sports, socialising and being competitive.	61
Providing and contributing to the family.....	62
Working and being occupied outside the home.	62
Fathering and modelling other masculine traits.	62
Life is Different Now – Analysis of Life Post Injury or Illness	63
Men are defined by what they do - Coping with occupational changes.....	63
Being proud of what you do - Self-esteem and occupation.....	65
The frustration of being dependent, eventual acceptance and moving on.	66
Financial dependence - No longer being a good provider.....	67
Institutional dependence - Being degraded by the process and people.	68
Health professionals should know what is wrong - Why should I have to tell them?	71
Physical and psychological dependence - Having to ask for help is the hardest thing.	72
Relationships change - Some people just can't cope.....	74
Worrying about others - I should be able to do more.....	74

Changes in the bedroom.	75
Changes in the parent - child relationship.	76
Most people don't know how to deal with it.	76
People with disabilities should be invisible.....	77
My life is not my disability - I am still a person.	77
Loss and change.	80
Masculinity and Summary.....	82
Chapter 5 - Discussion.....	84
Findings	84
Work: The measure of a man.	84
Depending on others and establishing control.....	86
Sex and sexuality.	89
Loss, change and renegotiation	90
Sports and socialisation	91
Masculinity and occupation.....	93
Strengths and Limitations.....	94
Areas for Further Research.....	96
Conclusion.....	97
References	98
Appendix A: Structure of the New Zealand Health and Disability System	111
Appendix B: Literature Included in Critical Review	112
Appendix C: Letter from University of Canterbury Ethics Committee	120
Appendix D: Counsellor Contact Information Sheet	121
Appendix E: Participant Information Sheet	122
Appendix F: Covering Letter to Organisation or Health Practitioner	124
Appendix G: List of Health Practitioners and Organisations Contacted.....	125
Appendix H: Poster	126

Appendix I: Covering Letter for Participants	127
Appendix J: Informed Consent Form	128
Appendix K: Interview Guide	129
Appendix L: Transcriber Confidentiality Form	130

List of Tables

Table 3.1: Justification of Interview Questions.....	49
Table 4.1: Demographic Data of Study Participants.....	58

List of Figures

Figure 3.1: Flow Diagram of Research Recruitment.....	45
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Abstract

Hegemonic Masculinity informs every aspect of a man's life regardless of whether they conform to the standards or reject them. Although masculinity informs occupational roles, it can also be seen as an occupation in its own right. Illnesses and injuries can challenge masculine status and result in loss of identity, as well as changing men's abilities, transforming their occupational roles and providing a challenge to their self-perception of masculinity. There are significant gaps in the literature; particularly regarding the impact health status has on masculine perceptions within a New Zealand context and the idea of masculinity as an occupation. This study goes someway to address these gaps.

A qualitative descriptive methodology was employed to understand and describe the stories of 12 men living with the ongoing effects of illness or injury. A general inductive approach to content analysis was undertaken to identify the key themes. The study's findings show illness and injury and the subsequent changes in occupational roles had a significant impact on participants' masculine perceptions. Study participants experienced loss in many areas of their lives and described being occupied in recreating and renegotiating their masculinity in varying areas such as work, personal relationships and social activities.

Further research, conducted within a New Zealand context, will be invaluable in validating the current findings in this area. The application of this knowledge is an area requiring extensive exploration and research. There is significant scope for healthcare professionals to gain understanding of men's relationship to, and their self-perceptions of, masculinity and to utilise and incorporate these findings into therapeutic settings, therefore gaining more valuable outcomes for their clients.

Chapter One – Introduction and Background to Study

Poor health and disability are areas of significant concern to New Zealand. The poor health of men has a cost to both the health and welfare systems in New Zealand, as men are more likely than women and children to die from a number of health and behavioural related conditions such as cancer, heart disease, violent acts and traffic accidents. However, men do not only die, but more often live with the ongoing effects of these illnesses and injuries. Men are over represented in weekly payments from both Accident Compensation Corporation (ACC) and Work and Income New Zealand (WINZ), and these payments make up a significant portion of each agency's financial outgoings (Ministry of Social Development, 2014; Wilson, Derrett, Hansen, & Langley, 2013). Additionally, the personal cost, in terms of financial, emotional, physical, social and reduced quality of life, impacts not only the men living with illness or injury, but also their families and loved ones (Johnson, 2009).

Although the effect illness and injury has on occupational roles has a corresponding effect on perceptions of masculinity, masculinity is also an occupation in its own right (Beagan & Saunders, 2005). I believe a better understanding of how men situate their masculine status in relation to chronic disability will assist healthcare providers, occupational therapists in particular, to better position their interventions within a context compatible with masculine ideals, which in turn may result in better rehabilitation outcomes for men and will create a follow on effect of placing less financial strain on the health and welfare systems of New Zealand.

Masculinity is largely a socio-cultural construct; it is produced through what men do and do not do (Beagan & Saunders, 2005). Definitions regarding what it is to be a man and what constitutes masculine behaviour are created and enforced by society as a whole. Definitions of masculinity have changed throughout history and more recently ideas of multiple masculinities and hegemonic masculinity have emerged (Connell, 2005; Connell & Messerschmidt, 2005). Hegemonic masculinity refers to the dominant ideal of the masculine male. These ideals are replicated and reinforced by society through the use of narratives, such as are found in various forms of media, regarding what is considered to be normal and acceptable behaviour for men (Stibbe, 2004). However, hegemonic masculinity is a dynamic view which is subject to change and able to be used in the area of rehabilitation effectively. Although masculine ideals

can be viewed as negative, and considered triggers for a variety of illnesses and disabilities (Oliffe & Phillips, 2008); the same ideals can be reformulated to frame rehabilitation outcomes in a positive manner. For example, the use of medication can be framed as taking control of an illness rather than being weak and needing pharmaceutical help. As Schopp, Good, Mazurek, Barker, and Stucky (2007) so eloquently state: “Given that men are at much greater risk for injury and that traditional masculine socialisation plays an important role in pre-injury risk behaviours, understanding the gender specific factors that relate to men’s recovery from serious injuries is essential” (p. 625).

By utilising a qualitative descriptive methodology, I explored the daily experiences of 12 men who lived with chronic disability as a result of acquired illness or injury, while maintaining a focus on masculinity and occupation. Occupation is not simply related to paid employment or unpaid work, but is “generally defined as the things people do on a daily basis...[Being occupied] is not only a basic human need, but is also essential to both the development and maintenance of all individuals” (MacKinnon & Miller, 2003, p. 91). Health is affected by occupation (Hocking, 2009; MacKinnon & Miller, 2003; Wilcock, 2003). A person’s sense of well-being and self-esteem is impacted when they are unable to engage in occupations that they consider to be meaningful (Stone, 2003). Occupational roles can be intertwined with life roles and are often the way in which people define themselves. Men frame their identity in relation to occupational roles and performance, both current and historical. A deterioration in occupational performance can be correlated to a deterioration in health (MacKinnon & Miller, 2003). Quality of life, health, and well-being are improved through participation in meaningful daily occupation.

In asking the research question: What effects do acquired illness and injury and subsequent changes in occupational roles have on men’s self-perceptions of masculinity? I will endeavour to understand how men view their own masculinity before and after experiencing ongoing impairments due to an acquired illness or injury. I will also explore participants’ views on how disability challenged their perceptions of masculinity. This research will contribute to the body of findings on the impact that illness and injury have on perceptions of masculinity, albeit in New Zealand men and with a focus on occupation, and will provide recommendations for further research and healthcare practice.

In the remainder of this chapter I will define and describe the key concepts in my research, these being: occupation, occupational roles, and masculinity. I will then explore the health and disability profile of men, and describe the health and disability systems in New Zealand. I will finish the chapter with a discussion regarding my own background and interest in the area of men's health.

Background

Occupation

Occupational therapists are primarily concerned with occupation, that is, what people do and do not do (Beagan & Saunders, 2005). Not only do people need to be occupied, but the occupations also must hold a purpose for the person(s) completing it. The knowledge that people need to be engaged in meaningful occupation is not a recent notion and reference to this is found often throughout history (Wilcock, 2003). In order to explain this need, and justify the professional practice designed to enable people to undertake the occupations that are important to them, various models of occupational therapy have arisen.

Occupation itself has also undergone scrutiny and has typically been divided into four categories of self-care, leisure, productivity and rest (Chapparo & Ranka, 1997). Although the terminology differs between models and theorists, the underlying concepts in many of these remain the same. In practice, however, occupation is rarely this simplistic and not all occupations fall precisely into these categories. What we do know is that people who experience deficit in any occupational area may benefit from engaging in the therapy process, but in order to do this, the process needs to be meaningful to them (Hocking, 2009).

As with models of occupational therapy, there are various definitions of occupation. The main concepts of this term are comprehensively summarised by the American Occupational Therapy Association.

Occupations are the activities people engage in throughout their daily lives to fulfil their time and give their life meaning. Occupations involve mental abilities and skills and may or may not have an observable physical dimension. Occupations always have some degree of personal meaning, have contextual, temporal, psychological, social, symbolic, cultural, ethnic, and/or spiritual

dimensions. Occupations reflect the unique characteristics of the person. A person is defined, to some extent, by the occupations in which he or she engages. A person's preferred occupations may change over time, depending on different factors or circumstances in his or her life. (American Occupational Therapy Association, 1997, p. 864)

Occupational roles.

Along with occupation, occupational therapists are also concerned with understanding a person's occupational roles. Occupational roles are defined as "patterns of behaviour composed of self-maintenance, work, leisure and rest activities" (Hillman & Chapparo, 1995, p. 88). A person's identity is inextricably intertwined with their occupational roles and these roles are often the measure by which we define ourselves. Roles have expectations attached to them, how to behave, perform and even what occupations should be completed with a role (Hocking, 2009). Amongst many others, men fulfil roles as fathers, brothers, sons, workers, husbands, lovers, providers and protectors.

Gender often has an impact on the types of occupational roles a person engages in (Beagan & Saunders, 2005; Du Plessis, 1994). Societal expectations as to what roles one should fill, depending on biological sex are commonplace. For example, within Western societies, men are traditionally seen as the breadwinners and women are in charge of the home (Beigi & Cheng, 2010; Du Plessis, 1994; Wada, Backman, & Forwell, 2010). These role expectations change over the course of time and are dependent on the socio-cultural environment of the era. For instance, over the last quarter century men have become "more involved in domestic occupations... whereas women are spending more time on paid occupations" (Wada et al., 2010, p. 92).

Gender is socially and culturally constructed. Socio-cultural ideals dictate how men and women are meant to behave at any one point in time and to a certain degree, what occupations they should undertake. "Gender is produced both individually and collectively through what men and women, boys and girls, do and do not do" (Beagan & Saunders, 2005, p. 161). However, although gender influences many occupational choices, gender is also constructed through occupation and is an occupation within itself. Through their study of 11 young Canadian men, Beagan and Saunders (2005) found that men were occupied with producing their own masculinity. Along with the more visible occupations designed to promote a masculine gendered appearance, men also

may engage in much less visible occupations that help produce masculinity: constant (but unacknowledged) bodily comparisons with other men, monitoring their speech to ensure its masculinity, actively hiding the effort required to produce a particular image, and concealing the fact that they care about their appearance at all. (p. 161)

Masculinity

A person is not, by definition, considered masculine just because they are born male. Masculinity is largely a socio-cultural construct. Definitions regarding what it is to be a man and what constitutes masculine behaviour are created and enforced by society as a whole. Definitions of masculinity have changed throughout history and ideas of multiple masculinities and hegemonic masculinity have emerged (Connell & Messerschmidt, 2005). Masculinity is seen as a set of values such as “courage, inner solidarity, adventure and considerable amounts of toughness in mind and body” (Donaldson, 1993, p. 644). Hegemony are the “ways in which the ruling class establishes and maintains its domination” (Donaldson, 1993, p. 645). Combining these two ideas is not without its problems, as is the case where the primary hegemonic group do not fit the typical masculine ideal.

There are multiple forms of masculinity that are examined within the literature. These forms vary across cultures, countries and institutional settings (Connell & Messerschmidt, 2005). Masculinity is not a singular practice; it is a combination of various traits and behaviours, which are organised into a hierarchical structure based on class, culture and social constructs. Society has created a fantasy of an ‘ideal’ masculine specimen, which is virtually impossible for the average man to live up to. Hegemonic masculinity is displayed in a number of ways. For example, dominance, competitiveness, risk taking, “aggression, bodily strength, stoicism, heterosexism, homophobia and misogyny” (Gray, Fitch, Fergus, Mykhalovskiy, & Church, 2002, p. 45). In the Western world the ideal version of a hegemonic male is a heterosexual, virile, able-bodied, well educated, upper class, white male (Gray et al., 2002; Stibbe, 2004). Not only is this dream man unrealistic, there are many contradictions within this fantasy, which mean it also becomes unattainable.

When looking at hegemonic masculinity in the context of disability, it is important not to confuse this concept with that of ‘ableism’. In the context of disability,

‘ableism’ is used to describe the preference for certain abilities, considered to be superior, which results in the discrimination and devaluation of the ‘less able’ (Hehir, 2007; Wolbring, 2008). Ableism is a societal attitude that asserts, for example, that it is preferable for a person to walk rather than using a wheelchair or crutches, “speak [rather] than sign, [or] read print [rather] than read Braille” (Hehir, 2002, p. 1). Although there are commonalities between the concepts, hegemonic masculinity goes beyond ableism incorporating ideals which include, but are not limited to, race, class, and culture as well as bodily appearance and physical capability (Connell, 2005; Donaldson, 1993; Gray et al., 2002; Stibbe, 2004).

The ideal of hegemonic masculinity is dynamic and subject to change at any time depending on internal and external influences. This can cause great confusion for the man when he is attempting to establish his gender identity (Connell & Messerschmidt, 2005; Donaldson, 1993; New, 2001). When discussing hegemonic masculinity, it is assumed that one group of men display dominance over both other masculine groups as well as women. It is clear, however, that gender is not the only factor involved when considering the concept of hegemony, there is a combination of influences which serve to establish control of one group over another, these include values (both internal and external), culture, race, religion and class. Connell and Messerschmidt (2005) described these influences as becoming more diverse, due in part to technological advances in media and travel. This description is demonstrated with immigration, one culture/race brings its own masculine ideals to a new country where they may or may not be similar to the ideal already in existence there. This introduction of new masculine ideals can cause conflict or a meld of ideas, which in turn can create a new paradigm of masculinity. As well as being concerned with the relationships between the different masculine groups it is also important to address the relationship between genders when considering hegemonic masculinity. Masculine can be described as the opposite of feminine, the relationship between these two genders is co-dependant; in order to define masculinity there must be a defined femininity and vice versa (Connell & Messerschmidt, 2005).

There are several theories about the influence women have on the notion of hegemonic masculinity. Along with the concept of opposites, it is believed that women are the focus of sexual prowess of the heterosexual man and men’s competitive nature regarding this provides a framework for hegemonic masculinity. Men compete to win the desires of women, to control and take care of them (breadwinning). The idea of the

perfect man does not seem to be created from within male groups themselves but from outer organisations such as the media, academics and people of standing such as religious leaders and medical professionals (Donaldson, 1993). The reality of the everyday man is not that of the masculine ideal. The fantasy of the ‘perfect man’ can be detrimental to the way men view themselves as there is increased pressure on how to act (Connell, 2005; New, 2001). It appears that the strain of becoming the perfect masculine specimen causes more harm than good to a man’s psyche. Even modern examples of the quintessential man are not without their contradictions, for example, sportsmen who do not engage in typically male behaviour such as drinking and fighting or who give up their careers for personal and family related reasons. Indeed, masculinity as a framework is contradictory (Coles, 2008; Connell & Messerschmidt, 2005). The ways in which men define themselves can be as damaging to their physical, mental and emotional being as they can be positive.

Masculinity in New Zealand

New Zealand is a relatively young country in terms of Western colonisation. In his comprehensive history of the Pākehā male in New Zealand, J. Phillips (1987) found that the promotion of New Zealand as a country to emigrate to was often specifically targeted at men who had skills in manual labour, and those who were disillusioned with the perceived feminisation of the male role in England. Significantly more men than women emigrated to New Zealand, and within the male population there were more unmarried than married men. Until World War One the total New Zealand population was made up of substantially more men than women. Statistically speaking, men were more likely to be in the company of other men than women. These statistics and the early environmental conditions of the country contributed to creating a masculine culture unique to New Zealand. This recent history of the Pākehā male has implications for the hegemonic ideal which exists today.

In New Zealand the hegemonic ideal is a real ‘kiwi bloke’ who is hard, tough and strong. This man plays rugby, takes risks, ignores pain and other symptoms, denies emotions, and celebrates and drowns his sorrows at the pub (Harding, 1998a; McKinlay, 2005; J. Phillips, 1987). Young New Zealand men need to prove their masculinity by taking part in high-risk behaviours, such as driving fast and abusing alcohol and drugs, often continuing these activities in later years “as a response to stress or feelings of uselessness” (Harding, 1998b, p. 11). It is these stereotypes that have

contributed to men's poor health outcomes and have obstructed their access to healthcare (Goodyear-Smith & Birks, 2003; Harding, 1998b; McKinlay, 2005). As with other countries, in New Zealand the concept of what is masculine is consistently changing and is often contradictory. For example, it can be seen as masculine to exert power over and dominate another person, as might happen in a fight. However, there is also a social drive that one is more of a man if one walks away from conflict. This can be very confusing especially for young men trying to come to terms with establishing their own masculine identity. Many men both consciously and subconsciously exhibit behaviours that are considered to be masculine in order to be considered 'real' men both by themselves and by society. Concepts of masculinity and what it means to be a man are closely entwined and therefore throughout this thesis the terms masculine and manly are used interchangeably.

Men's Health and Disability Profile

Men's health is defined as "a disease or condition unique to men, more prevalent in men, more serious among men, for which risk factors are different for men or for which different interventions are required for men" (American Men's Health Forum, as cited in McKinlay, 2005, p. 6). It is interesting to note that this definition of men's health is actually more a definition of men's poor health. Many of the illnesses, injuries and subsequent disabilities that affect men are behavioural in origin. Men are more likely to die from coronary heart disease, cancers, violent acts, ischemic heart disease, stroke, transport accidents and intentional self-harm than women (Brownhill, Wilhelm, Barclay, & Schmied, 2005; Charlton, 2001).

The health impacts of certain risky behaviours, which men engage in, such as smoking and drinking, are well documented. For example, smoking damages genetic material and causes stroke, blindness, cardiovascular disease, chronic respiratory and reproductive problems, is responsible for 94% of all lung cancer patients and 22% of male deaths in New Zealand (Cancer Society of New Zealand, 2010). According to the New Zealand Cancer Registry, there has been an 18.7% increase in new cancer diagnoses between the years 2000 and 2010. In 2010, males made up 52.1% of these new registrations and cancer was identified as the leading cause of death in males (Ministry of Health, 2010). In New Zealand, "men make up 77% of problem drinkers" (Harding, 1998a, p. 18) and alcohol is a significant contributor in hypertension, cardiovascular disease, stroke, traffic accidents, domestic violence and other violent

acts in men (Charlton, 2001; Docherty, 1998; Dudson, 1998; Goodyear-Smith & Birks, 2003). However, men do not only die from these illnesses, but more often live with the ongoing consequences of their actions. Given the poor health status of men, it is important to address the manner in which men cope with their illnesses or disabilities. Masculinity influences how men look at themselves in the world and this in turn influences their actions and behaviours. By looking at the way masculinity is affected by illness and disability, health professionals can better understand their clients, and better situate interventions within a masculine framework, which will assist in providing men with better health outcomes.

At this juncture, I would like to make note that I am aware that the words, patient, client and consumer are used interchangeably within literature to describe a person who is utilising health care services or who is under the care or supervision of a healthcare provider such as an occupational therapist. For clarity, I will be using the word client within my own writing to describe the aforementioned people. However, in regards to the research findings, the men interviewed will be referred to as participants.

Health and Disability in the New Zealand Context

According to the 2013 Disability Survey, 24% of New Zealanders identify as disabled. Disease or illness accounted for 42% of disabilities in adults¹, while accident and injury were responsible for a further 34% (Statistics New Zealand, 2013). Men account for a significant percentage of these statistics. There is considerable cost associated with disability both in terms of financial and quality of life considerations (Johnson, 2009; Schoen et al., 2011; Wilson et al., 2013). In order to understand how injury and illness might impact on a man's sense of masculinity, it is important to understand the systems within which he is operating.

Health and disability system.

New Zealand's health and disability system has undergone substantive change over the past three decades (Sheridan et al., 2011). The current health care system is made up of various organisations that manage plan and provide health care services to the New Zealand population (Ministry of Health, 2012)(see Appendix A). The majority of health funding is managed by 20 District Health Boards (DHB's) situated throughout the country (Gauld, 2011; Ministry of Health, 2012). The DHBs work within a publically

¹ For this purpose an adult is considered to be 15 years of age or older.

funded health budget set by the government. Although this funding is allocated based on population, there is extra targeted funding for certain groups of people, for example, Māori and those living with chronic illness. Although various minority or at risk groups are often targeted through health policy and funding, the Treaty of Waitangi² ensures a constant focus on health equity for Māori which is not reflected amongst other cultural groups (Sheridan et al., 2011).

Access to public hospital care is free for New Zealand citizens; although the services are limited due to the constrained health dollar. Primary healthcare is funded through a co-payment scheme, however pregnant women and children under the age of 13 are able to access free general practitioner visits (Gauld, 2011). The introduction of a capitation scheme has meant that higher subsidies are available to Primary Health Organisations (PHOs) for certain ethnic groups or those with low income or high health needs (Gauld, 2011; Sheridan et al., 2011), however these higher payments do not always result in a lower co-payment for these groups. Many men living with illness or injury access their health care through the public health system.

Accident Compensation Corporation.

ACC is a quasi-governmental organisation that provides no-fault personal injury cover for all New Zealand residents and people visiting New Zealand. ACC is publicly funded through employer and employee levies and various taxes such as in vehicle registration (Accident Compensation Corporation, n.d.; Gauld, 2011; Wilson et al., 2013). In addition to injury prevention education, ACC can provide funding for treatment and medical costs, and weekly compensation for loss of earnings (Accident Compensation Corporation, n.d.; Wilson et al., 2013). People with on-going disability due to injury are allocated a case manager who acts as a primary point of contact regarding most aspects of their injury claim. Weekly compensation for those who are unable to return to work for a period of time as a result of injury or accident makes up approximately 60% of ACC's total spending. For men who were engaged in paid employment at the time of injury, financial support may be primarily derived from ACC. Additionally, men make up 59% of people who are receiving weekly compensation (Wilson et al., 2013).

² The Treaty of Waitangi, signed in 1840 by the crown and various Māori chiefs, is often considered to be New Zealand's founding document and provides certain rights for Māori. These rights are reflected in New Zealand's health policies and procedures.

Work and Income New Zealand.

New Zealand has a well-established welfare system which began in 1898 with the introduction of a retirement pension (Sheridan et al., 2011; Shirley, 1994). Welfare payments are currently managed by Work and Income New Zealand (WINZ). WINZ is a government funded agency which provides financial assistance and employment services throughout New Zealand. Although not a part of the health system as such, WINZ provides asset and income based financial support for many people living with ongoing disabilities. Financial support is through a weekly payment called Jobseeker support –health condition or disability. There are significantly more men than women receiving this payment (Ministry of Social Development, 2014). For men who are living with disability arising from illness or disease, WINZ maybe the only source of income available to them. However, for those who have a partner engaged in paid employment the income thresholds may mean this funding stream is not available to them and therefore they are left solely reliant on their partners for financial support. WINZ also employs a case management strategy, although differing slightly from that of ACC. Clients of WINZ do not typically have the consistency of a single case manager rather, when making face-to-face appointments clients are seen in order of arrival, and phone enquiries are dealt with by call centre staff (Ministry of Social Development, n.d.).

My Interest

As a mature aged student, I graduated with a Bachelor of Occupational Therapy from Otago Polytechnic in Dunedin, New Zealand. I have always been interested in research as career path and had wanted at some stage to move into a research field. I developed melanoma in my final year of training and had to reduce my workload due to the treatment of this. I worked for a year and a half in the areas of needs assessment and rehabilitation and was then injured. My health situation meant that I could not continue to work full- time in the traditional areas of occupational therapy. Given it was only my physical ability and not my intellectual ability that was challenged, I decided to return to study, completing a Bachelor of Arts in Gender and Religious Studies. I chose these subjects as I was interested in gender and cultural issues, both as a woman working in the area of healthcare and from the gendered and cultural perspective of clients of a service.

When thinking of post-graduate study I wanted to pull my learning from both of my undergraduate degrees together. While looking at the ways in which I could achieve this I found there was a significant amount of research regarding women's experiences of health, primarily due to the extensive work achieved in the areas of women's and feminist studies; however there was much less information regarding men's experiences of gender and health. As a part of my gender major, I completed a paper in masculinities that I found really interesting. I did some further research and found that there was a Post-Graduate Diploma in Health Science endorsed with Men's Health available at the University of Canterbury and so I enrolled in this. The additional knowledge I gained while completing this diploma cemented my interest in the area of men, masculinities and health resulting in my choice of this area for further research.

Given the significant number of women employed in healthcare, particularly in the areas of nursing and allied health, I feel an understanding of how health status can impact on a man's masculine identity is an area that needs more research and deserves an increase in attention. I believe through this understanding that health professionals, both male and female, will be able to facilitate better health and rehabilitation outcomes for men. From an occupational therapy point of view, there is a clear link between health and occupation. An increase in knowledge can only be positive for both clients and practitioners. This view is supported by Hocking (2009) in her statement:

Enhanced knowledge of occupations will inform therapists' understanding of their clients as occupational beings, through greater appreciation of the meaning, demands and context of the occupations they aspire to. Thus informed, occupational therapists will be better equipped to use occupation therapeutically. (p. 140)

My own health status has meant I have had some invaluable insight into various health and support systems in New Zealand, along with challenges of living with chronic disability, albeit from a female perspective. I was very conscious of any biases my own experiences might bring to the study and spent a great deal of time analysing and becoming more aware of my own opinions and prejudices prior to starting interviews in order to be aware of the impact these might have on the information gained from participants. I addressed any issues that may have arisen from this study through the process of enhancing trustworthiness as described further in Chapter Three.

Summary

Many of men's poor health issues can be related back to issues of masculinity. As explained earlier in this chapter, both masculinity and disability can be seen as social constructs (Beagan & Saunders, 2005; Dowling & Dolan, 2001). Disability can be viewed as socially constructed, as when it is experienced in relation to the physical environment, and the attitudes and behaviour of others. Masculinity can also be viewed as socially constructed. Definitions regarding what it is to be a man and what constitutes masculine behaviour have been created and enforced by society as a whole throughout history (Beagan & Saunders, 2005).

In this chapter I have provided an introduction and background to my research. The following chapter will provide a review of the literature regarding disability and masculinity. In Chapter Three I will describe the methodology and methods I used to complete the study while in Chapter Four I will discuss the findings of my own research study. In the final chapter I will situate my research findings in the context of the existing literature base and provide a critique of these along with discussing the strengths and limitations of the study and suggestions for further research and healthcare practice.

Chapter 2 - Literature Review

As discussed in Chapter One; hegemonic masculinity informs every aspect of a man's life regardless of whether he conforms to the standards or rejects them. Although masculinity informs occupational roles, it is also an occupation in its own right (Beagan & Saunders, 2005). Illness and injury can challenge masculine status and result in loss of identity, they can also change men's abilities in many areas, transforming their occupational roles and providing a challenge to their self-perception of masculinity.

The theory of hegemonic masculinity is one that has been taken on board by varying disciplines; each one of these fields has defined the idea in their own unique way, which has resulted in different connotations being attached to this model. There is a limited amount of literature regarding what effect injury or illness has on how men view their masculinity. In addition, the literature is scattered between disciplines in areas such as sport, social sciences, disability, sex, rehabilitation, psychology, communication, occupation, and medicine. Regardless of methodology utilised, the particular focus of the study, or the location and cultural background of study participants, there is some homogeneity regarding hegemonic and traditional masculine values, and how illness and injury impact on these. These similarities are reflected in findings across the studies.

In this chapter I will discuss the methods employed to search for literature appropriate to the study. The literature was surveyed for rigour and quality, and the findings were thematically analysed and presented under the headings of: the male body; sport and disability; virility and sexual function; inability to protect and provide; avoidance and help-seeking; control, vulnerability and loss; and renegotiating masculinity. I will conclude this chapter with a discussion of the dominant themes, gaps in the literature and suggestions for further research.

Method

A literature review was conducted by searching online databases including CINAHL, Medline, PsycINFO, Web of Knowledge, Informa Healthcare, Scopus, Proquest Google Scholar, Index New Zealand and Te Puna. Subject headings used were combinations of 'masculinity', 'occupation', 'disability', 'injury' and 'illness'. Where subject headings were not available, keywords were used. These searches provided a

limited amount of literature. By combining the term ‘masculinity’ with specific disabilities such as ‘spinal cord injury’, ‘traumatic brain injury’, ‘prostate cancer’ and ‘depression’ a small number of further articles were identified. This was also the case when combining the terms ‘occupation’, ‘illness’ and ‘disability’ and then limiting the search to articles referring to males only. As masculinity in the New Zealand context was of interest, all search parameters were repeated with the added key word ‘Zealand’. Only peer reviewed, published journal articles were resourced for this review. Journal articles were selected based on the meta-criteria of the search strategy. The reference lists of pertinent articles were examined, and appropriate articles extracted based on title, along with peer recommended references, which were sourced from specific journals. A focus was maintained on occupation, and occupational therapy journals were considered of particular interest. Thirty-six articles that matched the search criteria were reviewed (see Appendix B).

Although there is a significant number of peer reviewed studies examining the effect disability has on occupational roles and in particular the effect these have on women, there is only a small amount of literature pertaining solely to men. There is an emergence of literature investigating the role of masculinity on health and healthcare practices; however the literature examining the effect of disability on masculine perceptions is limited. Much of the literature identified has been written over the last six years indicating a growing interest in this emerging field of study.

Results

The male body.

The male body is the primary vessel for masculinity practices and performance (O’Brien, Hunt, & Hart, 2005; Stibbe, 2004). Hegemonic masculinity promotes an ideal male body as strong, robust, dominant, physically active, competitive, independent, healthy, in control and sexually potent (Oliffe & Phillips, 2008; Rapala & Manderson, 2005; Shakespeare, 1999). The male body is often seen as an instrument to be utilised as a means to achieve certain goals. The “traditional masculine values of physical sacrifice and toughness [promote] notions of the body as a machine, a tool that should not feel pain or hurt” (Lindemann & Cherney, 2008, p. 114).

Men have been traditionally encouraged to not be concerned with their bodies, as people who take care of their bodies have been, and often still are, considered

feminine (Gray et al., 2002; O'Brien et al., 2005). There is social pressure on men to conform to typically masculine behaviours. For example, O'Brien et al. (2005) found in their study of 55 men, the ability to endure pain and the effects of illness or injury was considered a masculine attribute and was preferable to appearing weak to their peers by seeking medical advice. Although the findings were reasonably consistent across a variety of focus groups, the focus groups in this study had a minimal number of participants, varying from two to six participants. It is possible that the groups with two to three participants may not have yielded the quality of information found in groups of larger numbers.

Stibbe (2004), in his review of six American *Men's Health* magazines, found many masculine ideals such as being powerful, eating a lot of meat, drinking alcohol, not attending the doctor, and degrading others who do not conform to hegemonic ideals of masculinity, reproduced and disguised in the form of health advice. While this article focuses only on six, monthly issues of the American version of this magazine, it does allude to the large number of international versions, mentioning in particular the South African *Men's Health* magazine, as reproducing similar hegemonic ideologies. It appears from the article that these ideologies feature strongly throughout the various editions, which are continually reproduced in each copy, reinforcing these masculine ideals.

Social pressures such as are found in magazines and other forms of media and from peers can affect male health, with men ignoring their bodies in pursuit of other masculine ideologies such as being the breadwinner or fighting. Men's bodies are frequently seen as disposable, it can be seen as acceptable for men to drive fast, eat and drink to excess, go to war and be maimed or killed. The prospect that the body may not be able to comply with these demands is habitually ignored, and any man who speaks out against these notions can be seen as less of a man (Lindemann & Cherney, 2008; Stibbe, 2004).

Men's sense of masculinity is directly related to their bodies. The creation of masculinity through a male's bodily performance means that when the body cannot perform its masculine functions, as can be the case with disability, masculine status can become vulnerable (Lindemann & Cherney, 2008; Stibbe, 2004). Disabled men are commonly marginalised and stigmatised by society due to their inability to conform to mainstream beliefs of what it is to be a man (Taub, Blinde, & Greer, 1999). The disabled body does not conform to masculine norms and is therefore considered deviant

and abnormal. Common perceptions are that the disabled body is inferior, passive, messy, sick, weak, infantile, child-like, feminine and asexual (Gibson, Young, Upshur, & McKeever, 2007; Lindemann, 2010; Rapala & Manderson, 2005; Taub et al., 1999).

Men who adhere to hegemonic ideals appear to want to oppress groups that are not a part of their own; this is achieved through a system of degradation and domination (Gibson et al., 2007; Stibbe, 2004). A number of studies (Gibson et al., 2007; Ostrander, 2008; Schopp, Good, Barker, Mazurek, & Hathaway, 2006; Taub et al., 1999) found men's self-perception of masculinity can be decreased because of disability and this perception is then reinforced through societal values and behaviour. Gibson et al. (2007) found in their Bourdieusian examination of ten ethnographic case studies of men living with Duchenne muscular dystrophy (DMD), societal marginalisation such as inaccessible environmental and social spaces resulted in further *embodied* marginalisation of the men involved in the study. The robust argument presented by Gibson et al. (2007) is supported by Ostrander (2008), in his comprehensively member checked, researcher triangulated and peer reviewed study of 11 men who experienced spinal cord injury through gunshot wounds. Due to perceived lack of strength and physical appearance, men with disabilities are often not considered 'real men' both by themselves and society (Gibson et al., 2007; Ostrander, 2008; Schopp et al., 2006; Taub et al., 1999) and "do not automatically enjoy the power and privileges of non-disabled men" (Shakespeare, 1999, p. 61).

In addition to stigma and marginalisation, men with disabilities often experience a negative body image. That is, the man does not view his disabled body as adhering to traditional norms of build and attractiveness, instead viewing it as deviant and unfavourable. Along with initial impairments, injury and illness can continue to affect the body in various ways such as muscle atrophy. As the body changes, so does a man's sense of masculine identity (Jonsson, Aus, & Berterö, 2010; Ostrander, 2008; Rapala & Manderson, 2005). A change in body image has been found to negatively impact on men's identity, independence, relationships and sex lives (Ostrander, 2008; Rapala & Manderson, 2005; Schopp et al., 2006; Taub et al., 1999). In their general qualitative interview study of 24 male college (university) students, Taub et al. (1999) found one of the main ways to challenge these common stereotypes of the disabled body is by displaying it in a socially acceptable and masculine manner, for example, through playing sports .

Sport and disability.

Sport is considered the occupation of men (Lindemann & Cherney, 2008; O'Brien et al., 2005; Taub et al., 1999). Historically, particularly in western countries, boys have been encouraged to exert their 'manliness' by becoming involved in sport (Lindemann & Cherney, 2008; O'Brien et al., 2005). Different sports have a variety of levels of manliness attached to them, with those which utilise aggression, competitiveness and temerarious behaviours, such as rugby (league and union), football and basketball, holding more masculine value than for example, lawn bowls (Sparkes & Smith, 2002). The structures and physical abilities required in sports such as these support hegemonic masculinity through their innate sexism, homophobia, heterosexuality and the subordination of women and men who do not conform to the culturally acceptable norms, such as gay or disabled men (Gaskin, Andersen, & Morris, 2010; O'Brien et al., 2005; Rapala & Manderson, 2005; Sparkes & Smith, 2002).

By becoming involved with sport, disabled men challenge prevailing views of masculinity while closing the gap between the socially accepted hegemonic male and the marginalised and subordinated other (Sparkes & Smith, 2002; Taub et al., 1999). In their three year ethnographic study of quad (wheelchair) rugby, Lindemann and Cherney (2008) found the act of participating in a sport, such as quad rugby can challenge the views held by many people regarding those living with disability. The authors refer to these views as 'ableist' and found:

Participating in quad rugby is a communicative act that sends a message to the community of sport and beyond challenging ableist assumptions about disability, masculinity, and ability... these messages are communicated as much to the players themselves as to spectators, and they inform the rehabilitation of identity from self-loathing and stigma to acceptance and pride. (Lindemann & Cherney, 2008, p. 120)

The findings of Lindemann and Cherney (2008) support the findings of an earlier study by Taub et al. (1999) which looked at 24 male college³ students with varying forms of disability. Despite drawing participants from only one source (a disability service at one university), the age range (20-51 years) and differences in

³ This study was conducted in the United States of America. In America, universities are often known as colleges.

diagnosis and physical ability of the participants involved in this study were reasonably broad. The findings of Taub and colleagues are comparable to other studies of a similar nature, however, the convenience sampling method utilised may have had some impact on the results of this study due to the educationally motivated nature of the participants.

Engaging in sport also supports a hegemony among disabled men with players displaying “their willingness to sacrifice their bodies, claiming that they play rough and are always ready to take a spill for a loose ball... since these characteristics of sacrifice and toughness are viewed as part of a ‘macho’ and masculine image” (Lindemann & Cherney, 2008, p. 108). Gibson et al. (2007) found a similar hegemony within their study and also recognised the value of the wheelchair as an extension to the player’s body, for example,

wheelchair speed, power and manoeuvrability were markers of status and masculine power within wheelchair sports...physical fearlessness and aggression were valorised and demonstrated through using wheelchairs to engage in violence...the appearance of fearlessness coupled with technical prowess in manipulating one’s wheelchair was a key source of capital that helped sustain a dominant position amongst the residents. (p. 510)

As well as challenging negative stereotypes and providing a hegemonic framework for disabled men, involvement in disabled sports, such as wheelchair basketball, quad rugby and other disabled sports, provides a forum for discussion and the creation of new friendships and support networks (Gaskin et al., 2010; Lindemann, 2010; Lindemann & Cherney, 2008). Along with sporting practices, by socialising with other players, athletes also gain valuable information regarding the practicalities of daily living (Lindemann, 2010; Lindemann & Cherney, 2008).

The benefits of sporting involvement are not limited to friendship and information, with men expressing increased mood and motivation, sense of achievement, ability to maintain independence, feelings of empowerment (Lindemann & Cherney, 2008), “delayed onset of functional decline, improved ways of handling stress, greater fitness, improved body image, increased competence and self-esteem, and more social connections” (Gaskin et al., 2010, p. 204), increased psychosocial development, increased physical functioning, improved body image (Gaskin et al., 2010) increased self-esteem (Gaskin et al., 2010; Lindemann & Cherney, 2008) and the

ability to “reestablish their masculine identity” (Tepper, 1999, p. 48) through their participation in disabled sports.

Conversely some men, who had previously engaged in able-bodied sports, expressed experiencing less satisfaction from their involvement in disabled sports, and a belief that they “aren’t real sports, not really” (Sparkes & Smith, 2002, p. 270). The reinforcement of this belief from some spectators along with the need for assistance can negate the benefits of participation in disabled sports (Taub et al., 1999). In addition, involvement in disabled sports also served as a reminder to some athletes of their previous abilities (Sparkes & Smith, 2002). Similarly, in their case study of one man living with a spinal cord injury, Rapala and Manderson (2005) explored the idea that:

many disabled males are unable (due to the impairment) to perform masculinity through sport.... even those who may be physically capable of performing, may be unwilling to do so because of prevailing cultural stereotypes and low self-esteem, which may result in a self-imposed isolation and removal from social activities. (pp. 164-165)

In their case study of one man with mild cerebral palsy, Gaskin et al. (2010) found that participation in sport meant “he remained isolated and did not form intimate relationships, because he perceived himself as too busy with swimming” (p. 204). In this case the study participant was involved in the solitary sport of swimming rather than a team sport such as wheelchair rugby. Despite the differences in the cause of disability and the focus on only one study participant, the findings of these two case studies (Gaskin et al., 2010; Rapala & Manderson, 2005) are congruent with other studies in the area of sport, disability and masculinity.

Cultural perceptions also have an impact on the benefits that may be gained from participating in sports. Rugby Union has a significant place in the history of New Zealand and participation for boys has historically been compulsory within the schooling system (Park, 2000). In the only New Zealand study that could be found that fit the search parameter’s for this literature review; Park (2000) found in her study of boys and men with haemophilia in New Zealand that regardless of the ability to engage in some non-contact sports such as touch rugby and cricket, and the belief of mothers in particular that these were suitable substitutes, most of the boys and men interviewed

voiced the opinion that “the worst hassle about haemophilia is you can’t play rugby” (Park, 2000, p. 445).

For men living with disability, it may be that there are varying degrees of positive and negative aspects regarding being involved in sport, depending on the level of disability and what type of sport is engaged in. Regardless of whether involvement in disabled sports has positive or negative connotations for men living with disability; it is clear that for many men sport is positively correlated with masculinity and all sportsmen whether living with a disability or not, operate within a masculine framework which serves to establish and reinforce their masculinity, sexuality and adulthood so that they may be considered ‘one of the boys’ rather than being an observer of this ‘boys’ group alongside other excluded groups such as women (Rapala & Manderson, 2005).

Virility and sexual function.

Sex, sexual intercourse and sexuality are “an important area of human social and cultural experience” (Rapala & Manderson, 2005, p. 162). Yet this is an area that is often neglected by healthcare professionals due to the pervasive belief that the disabled body is an asexual body (Rapala & Manderson, 2005; Tepper, 1999). Literature that was reviewed regarding masculinity and sexuality (Burns, Hough, Boyd, & Hill, 2009; Shakespeare, 1999; Tepper, 1999), and penile and prostate cancer (Bullen, Edwards, Marke, & Matthews, 2010; Gannon, Guerro-Blanco, Patel, & Abel, 2010; Gray et al., 2002) establish that, often through the process of socialisation, boys are taught from birth that their masculine identity is symbolically tied to their ownership, control, size, and operation of their penis. The full or partial loss of erectile function can be considered a significant threat to this masculinity. These beliefs are supported and reiterated throughout various other articles that were reviewed and the impact disability had on male sexuality was a common theme (Gibson et al., 2007; Lindemann, 2010; Rapala & Manderson, 2005; Schopp et al., 2006; Schopp et al., 2007; Stibbe, 2004).

Many illnesses and disabilities, (for example, spinal cord injury (SCI), traumatic brain injury (TBI), and various forms of cancer) have an effect on male sexual functioning (Burns et al., 2009; Gibson et al., 2007; Gray et al., 2002; Schopp et al., 2006; Schopp et al., 2007; Tepper, 1999). However, “each person’s experience with disability and sexuality is different” (Rapala & Manderson, 2005, p. 163). For example Gray et al. (2002) conducted between four and five interviews each with three men,

living with prostate cancer, who were considered to embody traits and beliefs typical to the hegemonic male. The authors found in two of these cases that although sexual dysfunction was of some concern, it was not as much of a significant threat to the participants' sense of masculinity as first assumed. However, sexual dysfunction was of major concern to the third participant. The authors point out that attitudes toward, and adaption to, sexual dysfunction can depend on a man's own personal attitudes and beliefs toward sex and sexuality, along with their own sexual history prior to experiencing illness.

The type of injury or illness experienced can also impact on how men experience sexuality in relation to their disability. For example in their quantitative study of 33 men with TBI, Schopp et al. (2006), established TBI had "a profound affect on sexual performance and satisfaction" (p. 1156). Through the use of various empirical instruments such as the Conformity to Masculine Norms Inventory (CMNI), Gender Role Conflict Scale (GRCS), Functional Independence Measure (FIM), and Satisfaction with Life Scale, found that TBI had negatively affected sexual functioning, sexual desire, and impacted negatively on sexual aspects of body image. This study relied solely on the use of the above research instruments and therefore there were not any qualitative context to the results. Nonetheless, the findings are consistent with both other quantitative studies in the area of disability and masculinity that were reviewed (Burns et al., 2009; Good et al., 2006; Schopp et al., 2007) as well as qualitative studies in similar areas (Gannon et al., 2010; Lindemann, 2010; Tepper, 1999). However, the degree to which disability negatively impacted on participants' sexual functioning and the resultant impact of sense of masculine identity varied between studies. In part this variance related to the ways in which some men reframed or renegotiated their masculinity. The renegotiation of masculinity will be further discussed later in this chapter.

Despite the seeming importance of this issue, there is a consensus across prostate cancer studies that the spontaneity of sexual activity engaged in was paramount, with artificial sexual aids holding little appeal for study participants (Gannon et al., 2010; Gray et al., 2002; Jonsson et al., 2010). Gannon et al. (2010) warn it is more appropriate for health professionals to offer alternate ways of expressing sexuality rather than the addition of medical aids as

..by providing medication, such as Viagra, and physical aids, such as vacuum pumps, medical practitioners are in a sense colluding with powerful discourses that construct male sexuality in terms of penetrative sex. Healthcare practitioners need to be aware of how this practice can constrain the process of reconstructing masculinity and should be tentative in how they offer such interventions. (pp. 263- 264)

Study participants dealing with the effects of prostate cancer treatment (Gray et al., 2002), reframed their experience of impotence in differing ways. One looked at his ability to still love his wife and family, while still being viewed as attractive to the outside world, his sexual virility was expressed through his ability to flirt and arouse others rather than the act of sex itself. Another was worried about how he was able to please his wife and meet her sexual needs and this became the main focus of his illness. Study participants living with other illnesses and disabilities also utilised differing methods for addressing sexual function with some refocusing on pleasing their sexual partners and adjusting choice of intimate partners (Ostrander, 2008), or normalising fears and issues regarding sexual dysfunction (Burns et al., 2009), while others rejected the idea that they could be sexual partners at all and abstained from even attempting this type of activity (Gibson et al., 2007).

In their online quantitative study that investigated the links between sexual desire and depression in 201 men with SCI; Burns et al. (2009) found adjustment difficulties were higher amongst those men who had “incongruity between their sexual interest and performance capabilities” (p. 126). While Schopp et al. (2006) believed that

redefining attitudes about traditional ideas of sexuality and relationships with women may have the potential to improve overall satisfaction. Therapeutic interventions should focus on cognitively reframing maladaptive conceptions of masculinity while retaining and bolstering more adaptive facets, such as will, self-efficacy and motivation. An emphasis on individual agency in the context of greater interdependence would support men in optimising rehabilitation and adjustment. (p. 1161)

As well as the adjustment difficulties and high rates of depression in men with decreased sexual functioning, partners of these men are also affected, and relationships often deteriorate, particularly post injury (Burns et al., 2009; Schopp et al., 2006; Schopp et al., 2007; Tepper, 1999). Regardless of how it is addressed, it is clear that sexual functioning and sexuality are important to men's identity and attention to this area is vitally important to on-going well-being (Rapala & Manderson, 2005; Tepper, 1999).

Inability to protect and financially provide.

One of the main assumptions of hegemonic masculinity is a man's ability to protect and financially provide. "Marriage [has historically] triggered men's roles as economic providers" (Kilkey & Clarke, 2010, p. 3) and it can be commonly assumed, in a patriarchal society, men should be the breadwinners of the family (Jones & Curtin, 2010; Sparkes & Smith, 2002). Not only does this belief marginalise men, who as a result of disabilities are unable to work and economically provide for their family, but it also places undue pressure on them to adhere to this masculine ideal. However, many men strive to emulate this ideal with "work and earning potential [being] closely related to self-esteem and perceived masculinity among most men. Employment provides for men a sense of satisfaction, pride and respect" (Schopp et al., 2007, p. 626) and being disabled or unwell places "constraints on their performance of the male breadwinner role" (Kilkey & Clarke, 2010, p. 10).

The masculine ideal of providing for the family is not restricted to the Western world. In Africa, several studies have found the desire to provide for and maintain the family unit is seen as the primary reason for non-disclosure of HIV/AIDS status and the uptake of anti-retroviral medications (Mfecane, 2012; Siu, Seeley, & Wight, 2013; Wyrod, 2011). Disclosure of extra-marital affairs and the stigma of HIV/AIDS can result in the loss of employment and the family unit. Given the importance placed on procreation and providing for the family within the masculine construct of these men, many who test positive for the HIV virus conceal their status from others (Mfecane, 2012; Siu et al., 2013; Wyrod, 2011).

As previously stated, occupation (including employment) is directly related to a person's well-being and identity (Cecil, McCaughan, & Parahoo, 2010; Schopp et al., 2006). The inability to work can not only threaten a man's means of financial support it also threatens their place in society. Jones and Curtin (2010) conducted a two-year

mixed methods study of people living with TBI. From their participant pool, the authors selected the findings from 21 men to discuss, and reported that, “self-identity, autonomy and emotional well-being are all significantly impacted by the failure to resume previous vocational occupations or another meaningful and productive activity” (p. 1). Jones and Curtin (2010) identified the need to return to work or to “find something that provides structure and meaning to compensate for loss of occupational identity” (p. 8) as vital to maintaining well-being in men. The earlier the age of injury, the amount of work experience a man has and the higher a man’s educational level, are factors related to a greater likelihood of returning to work (Schopp et al., 2007). Returning to work is also associated with “greater marital stability as men who actively strive toward goals and success also possess particular traits that may reflect personal dynamism, motivation, and optimism” (Schopp et al., 2007, p. 630).

Along with supporting the breadwinner role, hegemonic masculinity supports the notion that men must be able to protect those who hold a more submissive status in their lives, for example family members, mothers, wives and children, in order to be considered a ‘real man’ (Stibbe, 2004). Decreased sense of safety and increased vulnerability are common themes among the literature with participants from various studies expressing feeling ‘less of a man’ due to their perceived inability to defend and protect both themselves and their loved ones (Gannon et al., 2010; Gray et al., 2002; Oliffe, Ogrodniczuk, Bottorff, Johnson, & Hoyak, 2012; Ostrander, 2008; Sparkes & Smith, 2002).

In addition to concerns surrounding inability to physically protect themselves and loved ones, some men also feel a responsibility to emotionally protect their families. Becoming a burden on families is of deep concern to men with illness and/or disabilities (Gibson et al., 2007; Ostrander, 2008; Tepper, 1999). This concern and belief about families ‘suffering’ often prevents men from sharing their worries, fears and needs and instigates decision making independent of significant others, such as wives, partners, parents and children, in their lives (Gibson et al., 2007; Jones & Curtin, 2010; Oliffe et al., 2012; Tepper, 1999).

Although this concern regarding the unnecessary burdening of family members can result in negative behaviours such as those described above, it can also create some positive outcomes, for example, the responsibility felt toward wives, mothers and other family members has resulted in help and health seeking actions, engagement in social activities otherwise avoided and countering suicidal ideations in men (Emslie, Ridge,

Ziebland, & Hunt, 2006; Gray et al., 2002; Kilkey & Clarke, 2010; O'Brien et al., 2005; Oliffe et al., 2012).

As well as illness and disability affecting masculinity, loss of masculine roles can lead to illness. Studies have shown depression can arise where “men are dislocated from provider and protector roles” (Oliffe et al., 2012, p. 506), for example, in circumstances such as divorce, or unemployment. In their grounded theory study of 38 Canadian men living with depression, Oliffe et al. (2012) found the risk of suicide was diminished through a re-engagement with the family and promoting a focus on protecting and fathering roles.

Fathering and the domestic sphere

Hegemonic masculinity promotes the home and domestic tasks as the domain of women (Kilkey & Clarke, 2010; Stibbe, 2004). With the exception of barbequing, women do the cooking, cleaning, laundry and childcare, while men take out the rubbish, mow the lawns, fix items around the house and engage in paid work outside the home (Gorman-Murray, 2008; Stibbe, 2004). Although this is a shifting paradigm, women are more likely to have moved their roles from housework to paid employment than men are to have moved into the domestic sphere and in certain areas, for example in rural communities, men are more likely to continue to hold on to traditional roles (Good et al., 2006; Gorman-Murray, 2008).

Practicalities following illness or disability often require men to forgo traditional roles and take on domestic roles, which can be socially considered feminine, such as house husband or home father (Jones & Curtin, 2010; Schopp et al., 2006; Schopp et al., 2007). These role changes can present “major self-image challenges to men” (Jones & Curtin, 2010, p. 1569). Jones and Curtin (2010) found one way of reconciling the role change was for men to continue “to place value upon aspects of their identity that conformed with hegemonic masculinity, rather than upon their participation in domestic chores, now a major aspect of their daily lives” (p. 1573), for example, by reframing domestic duties within a management, advocacy or responsibility framework (Jones & Curtin, 2010; Segal, 2005).

Despite referring information in “some studies indicating that post-injury divorce rates are not different from those in the general population [and that] ...some marriages become stronger after injury due to increased intimacy and higher levels of communication” (Schopp et al., 2007, p. 626), in the background to their American

study of 20 men living with SCI, these authors also found “marital relationships are particularly vulnerable after injury” (Schopp et al., 2007, p. 626). Financial strain and stresses attached to role reversals within relationships often result in the breakdown of relationships and changes in parenting roles (Kilkey & Clarke, 2010; Molyneaux-Smith, Townsend, & Guernsey, 2003; Schopp et al., 2006; Segal, 2005).

A father’s role in the family is socially situated as an economic provider (Kilkey & Clarke, 2010). Parenting involvement is usually comprised of play and leisure activities. Changes to these roles from playful dad to full-time caregiver father are generally through life circumstances rather than choice (Segal, 2005). Although some men have expressed positive outcomes with this role change, such as closer and more nurturing relationships with children, others found discord with changes in power dynamics within their relationships and having their parenting ability constantly questioned (Kilkey & Clarke, 2010). Inadequacies are often emphasised and adjustments to parenting styles can highlight the loss of ability to engage in ‘typical’ fathering activities such as rough and tumble games (Jones & Curtin, 2010; Kilkey & Clarke, 2010; Park, 2000; Segal, 2005).

In order to address these changes, some men develop different methods of reconciling their own masculine identities with the reality of their daily lives. For example, by not verbally acknowledging hands-on care giving work or engaging in tasks which are considered masculine, such as home renovations and unpaid community work (Jones & Curtin, 2010; Segal, 2005). The ways in which men negotiate the changes in domestic life and how they enact their masculine status in relation to these role shifts differs depending on age, race and cultural background. Despite the negative relationship between hegemonic masculinity and the domestic sphere, the privacy of the home can afford men space needed to renegotiate these roles (Good et al., 2006; Kilkey & Clarke, 2010).

Avoidance and help seeking

The social construct of hegemonic masculinity promotes a view that men should not pursue help seeking behaviour (O’Brien et al., 2005). This is particularly endorsed by stereotypes of men’s attendance at doctors. Men who adhere to norms of hegemonic masculinity are less likely to go to the doctor or take on activities that promote health, participate in regular health checks or screening programmes and are unlikely to ask for or accept help for their health when it is offered (Good et al., 2006; O’Brien et al.,

2005; Schopp et al., 2007; Stibbe, 2004). In the study described earlier in this chapter by Gray et al. (2002), one of the study participants described his dislike of attending doctors in terms of fear of what might be found, stating that if you “bring a human being in for a medical exam, you’re going to find something wrong with him” (p. 48).

There is presumption that men do not know much about their own health and it is women’s responsibility to monitor men’s health behaviour (O’Brien et al., 2005; Stibbe, 2004). This trend is commonly recognised with many health-marketing campaigns targeted toward partners, wives and mothers. The same study participant who was fearful of what the doctors might find during a consultation (Gray et al., 2002) demonstrated this lack of knowledge, and refused to further educate himself once a diagnosis had been made. It seemed the less this man knew of his illness, the more deniability he had regarding his loss of masculine ideals. Even once he did admit to some of his problems, he only shared them with women, seeking their assistance in hiding his difficulties from other men. Rather than admit his own limitations, another participant in the same study admitted he “relied on his wife to make him slow down” (Gray et al., 2002, p. 52), placing the onus of his health on her and hiding his lack of ability behind her demands to reduce his physical activity. The beliefs and behaviour of these two study participants is reflected within the findings of other studies in this review (O’Brien et al., 2005; Stibbe, 2004).

When faced with the possibility of illness, men often self-monitor and self-medicate rather than seeking out assistance from health professionals (Jonsson et al., 2010; Oliffe et al., 2010; Oliffe & Phillips, 2008). Illnesses such as depression are “associated with powerlessness and the uncontrolled expression of emotion” (Emslie et al., 2006, p. 2246). By seeking help for illness such as this men have to admit loss of hegemonic ideals such as “emotional control and a lack of vulnerability” (Emslie et al., 2006, p. 2246). This behaviour is reinforced by society with men who actively seek out help for depression being likely to “attract significant societal and self-punishment as a result for deviating from such masculine scripts” (Oliffe & Phillips, 2008, p. 195). By ignoring the problem it is hoped that it will go away (Brownhill et al., 2005). In the case of illness, the initial benefit of minimising harm to masculine status by not addressing health related symptoms can be surpassed by the added damaging effects caused by more severe illness (Mfecane, 2012; Oliffe et al., 2010; Siu et al., 2013; Wyrod, 2011).

Avoidance behaviour is commonplace with strategies such as overwork often employed by men. These behaviours are often reinforced by society, for example, with recognition from employers for hard work or not taking sick days (Brownhill et al., 2005). Despite these commonalities there are times when it is acceptable for a man to cease avoidance and engage in help seeking behaviour, for example, after a suitable amount of time coping with pain or when there is a visible physical injury. Another example is when help seeking is seen to be preserving future health or another more important part of hegemonic masculinity such as sexual function or ability to work (O'Brien et al., 2005). In the absence of these, men require a "means of legitimising their visit" (O'Brien et al., 2005, p. 515) to a doctor in order to save face. Pressure from wives or other significant persons or confirmation of a significant illness from peers is a suitable reason for this.

Control, vulnerability and loss

People who adhere to hegemonic masculinity promote dominance, and control. Vulnerability, weakness and loss of control are denied (Shakespeare, 1999) therefore "becoming ill, in and of itself, is a threat to hegemonic masculinity, in that it implies weakness and a lack of control over one's body" (Gray et al., 2002, p. 45). The vulnerability that accompanies illness and disability is a challenge to men's masculine identity (Emslie et al., 2006; Gannon et al., 2010). Being self-sufficient and in control are meritorious traits within hegemonic masculinity. Admitting the possibility of a health related issue can involve relinquishing control over a situation, something men who adhere to hegemonic masculine ideals in general, do not like to do.

Perceived loss of control can be situational, such as when dealing with illness or disability trajectory or environmental, as in rehabilitation or hospital settings (Schopp et al., 2007; Segal, 2005). Showing emotions, with the exception of a select few such as anger, is typically associated with female behaviour (Brownhill et al., 2005; Tepper, 1999) and men take pride in their ability to control this aspect of themselves (Gray et al., 2002). Loss of emotional control in particular, is seen as a sign of vulnerability and weakness. Weakness has stigma attached to it, as weak men can be considered to be feminine and not 'real' men (Burns et al., 2009; Oliffe & Phillips, 2008; Shakespeare, 1999).

However, control can be a positive attribute when addressing rehabilitation (Emslie et al., 2006; Schopp et al., 2007). For example Schopp et al. (2007) established

that men who exhibited strong control over their emotions achieved higher functional gains and this emotional control also had a positive correlation to marital stability. The same authors found that men who experienced high emotionality were less able to focus on functional tasks and goals which in turn obstructed the rehabilitation process for these men. Along with loss of control, illness and disability bring with them a sense of loss in many areas of a man's life.

Loss is a theme which ran throughout the literature and was evident in a number of areas. As earlier stated, many men define themselves in relation to their masculinity, therefore a loss of masculine status, as can happen in the case of illness or injury also means a loss of identity (Good et al., 2006; Ostrander, 2008; Rapala & Manderson, 2005; Sparkes & Smith, 2002; Tepper, 1999). Some losses may contribute to on-going losses in other areas for instance, men with disabilities are often considered to be weak and childlike, in essence they have lost their adulthood, this "loss of adulthood is associated with loss of status" (Rapala & Manderson, 2005, p. 170). Illness and disability can lead to loss of sexual ability and the role of sexual being and partner (Ostrander, 2008; Tepper, 1999). Loss of paid employment leads to loss of financial security and losses of the worker and breadwinner roles (Segal, 2005). Stress arising from these losses can then lead to relationship breakups and consequently further losses of the husband and father roles (Kilkey & Clarke, 2010; Molyneaux-Smith et al., 2003; Segal, 2005).

By allowing others to assist in daily life and rehabilitation, men give up their autonomy (Schopp et al., 2007). Other areas where loss is experienced are in strength, self-reliance, independence, social inclusion as 'one of the boys', and leisure pursuits (Ostrander, 2008; Schopp et al., 2006; Tepper, 1999). In addition to their own feelings of loss, men need to address other people's reactions. Friends and family often regard men who experience illness or disability as different and these changes in attitudes can be difficult for men to negotiate. A significant number of men struggle with these losses and as a result, feelings of frustration, depression and substance abuse are common (Good et al., 2006; Molyneaux-Smith et al., 2003; Schopp et al., 2007; Tepper, 1999). Some of the ways men could address these losses could be through adjusting, re-evaluating or simply coming to terms with the loss.

Renegotiating masculinity.

The literature identifies two main ways of coping with the challenges to masculinity provided by illness and disability. These are to reject dominant forms of masculinity or to reformulate and renegotiate masculine ideals in a manner that is consistent with the new situation (Emslie et al., 2006; Gibson et al., 2007; Gray et al., 2002; Jones & Curtin, 2010; Kvigne, Kirkevold, Martinsen, & Bronken, 2014). Although discussed under slightly different names, the latter is most predominant in the literature.

In order to combine elements of hegemonic masculinity and redefine masculinity to suit the man's individual circumstance, emphasis is placed on constructs of masculinity that are still achievable (Gray et al., 2002; Jones & Curtin, 2010; Shakespeare, 1999) and a focus is maintained on making the disability fit the man's existing value set (Gray et al., 2002). Examples of these could be conceptualising illness or disability as a heroic struggle for which strength is required to overcome adversity (Emslie et al., 2006) or promoting increased knowledge around illness or disability as a form of control (Gray et al., 2002; Jonsson et al., 2010).

Along with focusing on attainable sections of hegemonic masculinity, the adjustment of meanings attached to some areas is also a method utilised when renegotiating masculine status (Gibson et al., 2007). By using traditional hegemonic male role models, the message can be portrayed "that it takes courage for men to ask for help. This position trades on the masculine ideal that confronting problems is gallant and rational, rather than associating help-seeking with weakness" (Olliffe & Phillips, 2008, p. 199). Another study found that TBI participants can "accommodate self-care and domestic tasks by emphasising key masculine identity components such as community leadership, mateship, stoicism and self-reliance" (Jones & Curtin, 2010, p. 10).

In their qualitative secondary analysis study of 16 men with depression, Emslie et al. (2006) found an integral part of recovery was the reconstruction of a masculine identity and a "valued sense of self" (p. 2255). Emslie et al. (2006) gained the data for their study from the data collected from a larger study that included women, however the secondary study focused solely on data collected from men with a range of ethnic backgrounds and sexual preferences. Although the authors gave some discussion on the impact being of ethnic or sexual minority had on study participants' experiences, five of the 16 men in the study had a diagnosis of bipolar depression; it may have been

beneficial for the authors to address any possible differences in data arising from the two different diagnoses. The adjustment of traditional beliefs regarding masculinity has been identified as a contributor to the rehabilitation outcomes of participants in several studies (Burns et al., 2009; Emslie et al., 2006; Jones & Curtin, 2010; Schopp et al., 2007). Burns et al. (2009) reported a decreased body image and increased loss of identity in men who were unable to adjust their pre-injury beliefs regarding hegemonic masculinity, while Schopp et al. (2007) found that study participants with SCI who did not, modify their gender schemas after their injury experienced a reduction in rehabilitative outcomes, an increase in problem use of alcohol, and a decrease in life satisfaction.

Finding space where men can still embody masculine ideals regardless of their illness or disability is a growing area for rehabilitation. There has been some success in utilising this approach for example in the Australian organisation 'Mensheds' which

...works with, rather than change traditional masculine scripts, highlighting the value of camaraderie, group productivity, and achievement for elderly men who experience depression... By allowing men to be 'one of the boys', regardless of whether they are 'boys with depression' stigma can be reduced and a renewed sense of identity and purpose are often accomplished. (Olliffe & Phillips, p. 199)

Purpose is an important component of all occupations. Being involved in purposeful activity can also contribute to hegemonic status; this concept is supported by Jones and Curtin (2010) in their previously described study. When discussing one of the participants involved in their study, the authors noted he could "re-occupy a hegemonic masculine identity through extensive community work" (p. 7). Associations between old and new occupations can assist in framing new activities within a masculine framework. The substitution of one activity for another within a similar grouping allowed for the participant to still feel involved while allowing for limited physical capacity. Segal (2005) also noted the importance of linking new roles to previous roles using an example of advocacy. The participant in this study had previously advocated for his wife in a number of settings, when the situation required that he became a full-time father, the participant transferred his role as an advocate for his wife to one of advocate for his sons.

Summary

There is a dearth of research on how men “define and express their masculinity in relation to illness [and disability]” (Gray et al., 2002, p. 45). Practices of hegemonic masculinity are not necessarily those followed, but are a description of an ideal “which most men felt they were expected to conform to and reproduce, or to justify their rejection of” (O’Brien et al., 2005, p. 515). It is perhaps ironic that the behaviours and actions, which are the very essence of hegemonic masculinity, for example, risk taking and aggression, are also those that often lead to the illness and disabilities, which serve to challenge men’s self-perceptions of their masculine status (Good et al., 2006; Oliffe & Phillips, 2008; Shakespeare, 1999).

Illness and disability can challenge masculine status and result in loss of identity (Good et al., 2006; Ostrander, 2008). Issues men face “after sustaining a debilitating permanent disability challenge the very essence of their male identity, often creating an identity crisis” (Good et al., 2006, p. 166). Identity and occupation are inextricably intertwined. Sparkes and Smith (2002) found “with each identity loss... the preservation of valued past [and] performing identities becomes increasingly difficult (p. 272). By restoring and maintaining occupational identity, men are able to better cope with their illness or disability (Braveman & Helfrich, 2001; Jones & Curtin, 2010; Segal, 2005).

The reconstruction of self-identity through occupational roles is a vital part of a successful rehabilitation outcome (Jones & Curtin, 2010). Occupational identity is formulated as a “sense of who one is and wishes to become” (Keilhofner, 2002 as cited in Phillips, Kelk, & Fitzgerald, 2007, p. 164). Public perception of masculinity is important to many men. Paradoxical information regarding masculine ideals are commonplace, for example, assistance provided in the form of ‘mateship’ does not present a challenge to masculinity, however intervention regarded as ‘help’ does (Jones & Curtin, 2010).

Hegemonic Masculinity informs every aspect of a man’s life regardless of whether they conform to the standards or reject them. Disability and illness change men’s abilities in many areas, transforming their occupational roles and providing a challenge to their self-perception of masculinity. Although many aspects of masculinity pose serious threats to the health of men, there are facets of the masculine construct such as determination, independence, focus and ability to rise to a challenge, which can

be utilised to enhance rehabilitation outcomes (Good et al., 2006; Schopp et al., 2007). There is significant scope for healthcare professionals, occupational therapists in particular, to gain understanding of men's relationship to and their self-perceptions of masculinity and to utilise and incorporate these findings into therapeutic settings, therefore gaining more valuable outcomes for their clients.

As there is a limited amount of research into how men combine illness and disability with masculine status there is much potential for further research. Literature is currently spread across disciplines and is focused on a small number of illnesses and disabilities. Studies that support the present literature will be invaluable to validate, explore, explain describe or discuss the current findings in these areas. In addition, new studies which explore the narratives of men experiencing a wide range of illnesses and disabilities will also be beneficial to understanding how men view themselves within a masculine framework. The application of this knowledge is also an area requiring extensive exploration and research.

Within this chapter I have reviewed and critically appraised the existing literature base on the impact disability has on masculinity and masculine perceptions. There is a clear gap in the literature regarding information specific to the New Zealand context with only one article (Park, 2000) able to be sourced. Although there is some literature available regarding the impact masculinity has on health and health outcomes, there is very little literature regarding the impact chronic illness and injury has on men's self-perceptions of masculinity. In the next chapter I will describe the methodology and methods I employed within my study.

Chapter 3 - Methodology and Methods

In this chapter I will describe the methodology and the methods chosen to conduct this research. Bogdan and Biklen (2007) refer to methodology as the “general approach a researcher takes including both the data collection techniques and the theoretical assumptions they bring to the study” (p. 273), while methods are the specific processes undertaken in order to complete the research and are consistent with the methodological approach. I recognise that various terms are used to describe aspects of methodology and these terminologies are often used synonymously. In order to avoid confusion, for this research, I will defer to Bogdan and Biklen’s definition and will use the word *methodology* to describe the various research traditions or strategies (Bogdan & Biklen, 2007; Denzin & Lincoln, 2011) which include, but are not limited to, grounded theory, phenomenology and qualitative descriptive studies. The term *paradigm* will be used to describe the theoretical framework which informs and guides the research (Bogdan & Biklen, 2007; Mackenzie & Knipe, 2006). Within various literatures a paradigm is also referred to as a knowledge claim, world view and interpretive or conceptual framework (Bloomberg & Volpe, 2012; Mackenzie & Knipe, 2006). Common paradigms are positivism/ post positivism, interpretivism/ constructivism (sometimes referred to as social constructivism), transformative, critical theory and pragmatism (Bloomberg & Volpe, 2012; Denzin & Lincoln, 2011; Mackenzie & Knipe, 2006). These concepts will be discussed further in the next section of this chapter.

The purposes of this study are twofold. The first purpose was to understand how men view their own masculinity before and after an acquired illness or injury. The second was to explore how disability challenged men’s perceptions of masculinity. As discussed in Chapter One, I believe a better understanding of how men situate their masculine status in relation to chronic disability will assist healthcare providers, occupational therapists in particular, to position their interventions within a context compatible with masculine ideals, which in turn may result in better rehabilitation outcomes for men. In order to explore this phenomenon, the research question was asked: What affects do acquired illness and injury and subsequent changes in occupational roles have on men’s self-perceptions of masculinity?

Within this chapter I will discuss why I chose to undertake a qualitative study and my choice of a qualitative descriptive methodology and constructivist paradigm

along with the ontological and epistemic foundations of these. I will then describe the methods undertaken in conducting this study. The methods section will include the ethical considerations of the study, sampling method, inclusion and exclusion criteria, participant recruitment, data collection and analysis and issues of trustworthiness.

Methodology

Why qualitative research?

Qualitative research typically encompasses naturalistic inquiry. Naturalistic inquiry involves studying a phenomenon in its natural state without any preconceived ideas regarding the nature of the phenomenon in question (Lincoln & Guba, 1985; Sandelowski, 2000). Qualitative research is concerned with understanding descriptive data gained from the subjective view point of study participants and is utilised within many academic disciplines (Bogdan & Biklen, 2007; Denzin & Lincoln, 2011; Lincoln & Guba, 1985; Merrill, 1985). Within health sciences, qualitative approaches are often used to enable “researchers to delve into questions of meaning, examine institutional and social practices and processes, [and] identify barriers and facilitators to change” (Starks & Trinidad, 2007, p. 1372). The understanding of these can be invaluable in the practice of client-centred occupational therapy (Gewurtz, Stergiou-Kita, Shaw, Kirsh, & Rappolt, 2008) which is relevant to me given my professional and educational background, and research objectives.

My own back-ground is in health science, occupational therapy and gender studies. My interest in undertaking this research was to bring these areas together and speak with men who experience an illness or injury which has resulted in a chronic disability. I wanted to understand how the men I spoke to viewed their own masculinity before the acquired illness or injury and to explore if and how the subsequent disability and changes in occupational roles challenged and/ or changed their self-perceptions of masculinity. Given that qualitative research explores the everyday experiences and perceptions of people in the world (Magilvy & Thomas, 2009) and the qualitative researcher speaks with people about how they experience, perceive, apply meaning to and make sense of their lives (Bogdan & Biklen, 2007; Denzin & Lincoln, 2011; Patton, 1990), I felt that a qualitative research approach would be appropriate to address my research question.

There are a number of research methodologies that fall under the umbrella of qualitative research. Each of these methodologies has its own philosophical assumptions, mode of inquiry and research goal (Bloomberg & Volpe, 2012; Corbin & Strauss, 2008; Starks & Trinidad, 2007; Wilding & Whiteford, 2005). I reviewed different types of qualitative methodologies and decided that a qualitative descriptive methodology would be most applicable to answer my research question.

Why a qualitative descriptive design?

The information I was interested in and my research question impacted on the choice of methodology. It was fairly simple to eliminate many of the different methodologies based on my research question and goal. For example, my research question did not involve developing a theory or theoretical framework such as would be the research goal in a grounded theory approach (Corbin & Strauss, 2008; Starks & Trinidad, 2007). Although there is both a disability and male culture within New Zealand, my question did not address either of these cultures or their ways of life in depth as it would if I was utilising an ethnographic methodology (Bloomberg & Volpe, 2012). My question also did not focus on language and how it is used, such as found in discourse analysis research (Starks & Trinidad, 2007). As previously stated, I was interested in what men living in New Zealand said about their lives both before and after their illness or injury. I wanted to establish if there was a difference in their lives and occupational roles, and how these differences might impact on the way they viewed themselves as men. As I researched various methodologies, I found aspects of my research question fitted in very closely with both phenomenological and qualitative descriptive approaches. Within a phenomenological approach the goal is to examine the meaning of a *lived experience*. Along with a textual description, a phenomenological approach also develops a structural description in order to develop a deeper understanding and capture the *essence* of the phenomenon that is experienced (Bloomberg & Volpe, 2012; Parse, 2001; Starks & Trinidad, 2007; Wilding & Whiteford, 2005). Although a phenomenological approach could have been used, there were aspects, such as the comparative element, of my research that did not fit within this framework. As such I ultimately decided that a qualitative descriptive design would provide a more suitable methodology.

Qualitative description is gaining favour as a methodological study design in healthcare research, particularly within nursing literature (Brown, 2012; Magilvy &

Thomas, 2009; Milne & Oberle, 2005; Parse, 2001; Sandelowski, 2009; Sullivan-Bolyai, Bova, & Harper, 2005). Although not a new methodological design, the use of qualitative description has seemingly increased since Sandelowski (2000) wrote her article titled: *Whatever happened to qualitative description?* As an occupational therapist, I felt that a qualitative descriptive design would be appropriate for my study because occupational therapists are concerned with occupation and how their clients experience their lives in the real world (Tomlin & Borgetto, 2011). A qualitative descriptive design allows for a “clear description of a specific phenomenon or experience from the perspective of the experiencing [person]” (Magilvy & Thomas, 2009, p. 299). As I previously stated in my introduction to this chapter, I believe the knowledge gained from this research is important because a better understanding of how men situate their masculine status in relation to chronic disability will assist healthcare providers, occupational therapists in particular, to position their interventions within a context compatible with masculine ideals, which in turn may result in better rehabilitation outcomes for men. Chenail (2011) espoused a similar view and believed that by understanding the experience of the client, healthcare providers can “learn how patients’ particular worldviews can shape their perspectives on themselves, their caregivers, and their lives [and] appreciate how patients’ culture can help shape their experiences as well as how patients engage with healthcare organisational cultures” (p. 1174). Two reasons for selecting this methodology were the rich description produced through a qualitative descriptive design and straightforward presentation of findings which can be easily understood by clinicians and lay people alike (Sandelowski, 2000; Sullivan-Bolyai et al., 2005).

A qualitative descriptive study design allows researchers to understand and describe people’s stories while staying *closer to their data*, that is, there is minimal interpretation of the data, or as described by some authors, *low inference interpretation* of the data gathered (Milne & Oberle, 2005; Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000, 2009; Sullivan-Bolyai et al., 2005). Data are not viewed through a specific interpretive process; rather the findings remain a rich and accurate description of events that can be agreed upon as factual by any person privy to the information, regardless of which hermeneutical method they prefer (Magilvy & Thomas, 2009; Neergaard et al., 2009; Sandelowski, 2000; Sullivan-Bolyai et al., 2005). Its eclectic nature means qualitative descriptive research can draw knowledge and processes from other methodologies without becoming defined as such (Brown,

2012; Magilvy & Thomas, 2009; Neergaard et al., 2009; Sandelowski, 2000, 2009; Sullivan-Bolyai et al., 2005). The patterns and themes arising from a life event or experience are the focus of study within a qualitative descriptive approach (Parse, 2001).

Which paradigm?

As stated in the introduction, research is informed and guided by a theoretical framework known as a paradigm. Bogdan and Biklen (2007) defined a paradigm as a “loose collection of logically related assumptions, concepts, or propositions that orient thinking and research” (p. 24). There are many different paradigms; each providing a different lens with which to view and guide research and thought (Bogdan & Biklen, 2007; Denzin & Lincoln, 2011; Mackenzie & Knipe, 2006). No paradigm provides more truth than another; however certain paradigms are more suited to specific methodological frameworks than others. For example a post positivist paradigm espouses a cause and effect relationship which can be observed and measured, therefore this paradigm is found most often within quantitative research (Denzin & Lincoln, 2011; Mackenzie & Knipe, 2006). My own study falls under a constructivist paradigm.

A constructivist (also known as interpretivist) paradigm views people’s understanding of the world as being constructed by individuals and society. Knowledge does not happen in a vacuum, the interactions that people have with their social, cultural and physical environments along with their own personality and coping skills contribute to the knowledge they have about the world and how they construct their own realities (Creswell, 2013; Denzin & Lincoln, 2011; Mackenzie & Knipe, 2006; Schwandt, 2000). As explained in the introduction chapter, both disability and masculinity can be seen as social constructs (Beagan & Saunders, 2005; Dowling & Dolan, 2001). Disability can be viewed as socially constructed, as when it is experienced in relation to the physical environment, and the attitudes and behaviour of others. Masculinity can also be viewed as socially constructed. Definitions regarding what it is to be a man and what constitutes masculine behaviour have been created and reinforced by society as a whole throughout history (Beagan & Saunders, 2005). As my research question addresses the affect chronic disability has on men’s self-perceptions of masculinity and these self-perceptions were constructed by and are unique to the men I have interviewed, it is most appropriate to engage a constructivist paradigm for my study.

Ontology.

The ontological position of the researcher refers to the assumptions the researcher holds regarding the nature of what is real in the world; that is, how we know what we know (Lincoln, Lynham, & Guba, 2011; Parse, 2001; Schwandt, 2007). Within a qualitative descriptive study design the underlying assumptions are that people “create social networks... can describe retrospective and prospective life events... [and that] patterns and themes surface through intense study of phenomena” (Parse, 2001, p. 57).

Ontological positions can also be referred to as being relativist or realist. A realist ontology assumes one truth which can be objectively observed, whereas a relativist ontology asserts there are multiple truths (or realities) and that these realities are subjective and equally valid (Bloomberg & Volpe, 2012; Lincoln & Guba, 1985; Lincoln et al., 2011; Schwandt, 2007). As with my research, where each man interviewed discussed his own perception of masculinity created through his own experiences and knowledge, a constructivist paradigm typically accepts there are multiple realities, that is, a relativist ontology (Denzin & Lincoln, 2011; Lincoln et al., 2011).

Epistemology.

Epistemology refers to the relationship between the researcher and the person or people being studied and the role of the researcher within the research study (Creswell, 2013; Denzin & Lincoln, 2011; Lincoln & Guba, 1985). The epistemological position is influenced by both the paradigm and ontology of the study. Within a constructivist paradigm and relativist ontology there is an assumption that the researcher is interactive; that is, along with the study participant(s), the researcher brings his or her own subjective knowledge and experiences to the research process in order to co-create an understanding of the phenomenon in question. This assumption is referred to as a subjective and transactional epistemology (Denzin & Lincoln, 2011; Lincoln et al., 2011).

Summary.

The paradigm and methodology selection is driven largely by the beliefs of the researcher and the research question. Given the explanations above, I am conducting a naturalistic inquiry, using a qualitative descriptive methodology, a constructivist

paradigm, relativist ontology and a subjective and transactional epistemology. However the construction of a research study does not finish with the methodology section. A good study design also utilises methods which are congruent with the study methodology (Bogdan & Biklen, 2007; Parse, 2001). In the next section of this chapter I will discuss the research methods I utilised and how my method choices are consistent with my methodological selection.

Methods

Ethical considerations.

Prior to data collection, on August 10, 2012, I received ethical approval for my study from the University of Canterbury Human Ethics Committee (see Appendix C). There are many ethical issues which need to be taken into consideration throughout a research study (Creswell, 2013). While there was no apparent risk to physical well-being, it was important to realise that for people with physical limitations, even sitting down in one position for a period of time can cause discomfort. Every effort was made to ensure the participants' comfort and any issues were addressed on a case-by-case basis. For example, one participant was highly allergic to chemical smells, such as perfume, deodorant and hair products, due to this I made sure I was not wearing any of these when I met with him. A list of counsellors was available to study participants in the event that any mental or emotional distress arose (see Appendix D). Along with considerations of informed consent as discussed in the data collection section, participants had the opportunity to take breaks and also had the right to withdraw from the study at any time with no repercussions.

While it was not anticipated that moral or cultural offence would be given, when working with a potentially vulnerable group such as those experiencing illness and/or injury, it was important to consider the possibility of this occurring. As a part of the recruitment process, participants were given contact details for me as well as the study supervisors. If they had any concerns in the first instance they were asked to raise them with me. However if they were uncomfortable with this they were also able to raise them with the supervisors and/or the Chair of the Ethics Committee.

Study results will be made available to participants, either in an abridged or full format as requested by participants once the thesis is submitted. Along with a master's

thesis being compiled, participants were made aware the data will also be used for publication in peer-reviewed journals.

Research sample.

Within qualitative research the sample of participants can vary in size depending on the purpose and type of research being undertaken (Patton, 1990; Sandelowski, 1995b; Suzuki, Ahluwalia, Arora, & Mattis, 2007). Literature regarding sample size within a qualitative descriptive study is inconsistent and ranges from no set number of study participants (Parse, 2001), to between three and five and ranging up to 20 participants (Magilvy & Thomas, 2009). When taking into account the method of data collection, in this case semi-structured interviews, Kvale (1996) found that between five and 25 participants would be the required sample size range. While estimating the number of participants I would require for my research I also took into account my method of data analysis. Interviews were to continue until *thematic saturation* (also known as data saturation or informational redundancy) had been reached, that is, no new *themes* or topics of interest emerged from interviews (Lincoln & Guba, 1985; Sandelowski, 1995b). Themes will be discussed further in the data analysis section of this chapter. When using the criteria of thematic saturation, a researcher often utilises a larger number of study participants (Suzuki et al., 2007). I therefore assumed the larger range of participants being between five and 25 men (Kvale, 1996). In this study, it appeared thematic saturation occurred after nine interviews, however I considered it appropriate to conduct several more interviews to be certain saturation had been attained. In total twelve men were interviewed. The participants will be described further in Chapter Four.

Sampling.

Typically within qualitative research, participants are purposefully selected in order to study a phenomenon in an in-depth manner (Patton, 1990). Within qualitative descriptive study design purposeful sampling is often used in order to recruit participants who have the knowledge to provide a rich description of experiences appropriate to the study (Magilvy & Thomas, 2009; Patton, 1990; Sandelowski, 1995b, 2000, 2009). This study was looking at self-perceptions of masculinity before and after an acquired illness or injury. As such, prospective participants who were deemed to have in-depth and rich information in this area were men who had experienced an

acquired illness or injury that had an on-going impact on their lives over at least six months. These inclusion criteria will be discussed further in the next section.

A subset of purposeful sampling is snowball sampling also known as snowball recruitment or chain referral sampling. Snowball recruitment involves asking potential participants if they can suggest other potential study participants and is helpful in locating hard to access populations (Biernacki & Waldorf, 1981; Creswell, 2013; Patton, 1990). Rather than asking for details of people to contact, I asked the participants to pass my details on to anyone that they thought might be interested in the study. This technique was helpful in accessing three respondents who were interested in becoming involved in the study but had not been made aware of it through the advertising I had previously done. My utilisation of purposeful sampling strategies influenced the inclusion and exclusion criteria as well as the way in which I recruited study participants.

Inclusion and exclusion criteria.

Inclusion criteria involved men who had experienced the on-going impact of injury or illness over at least a six month time period. That timeframe was determined on a pragmatic basis rather than being theoretically or empirically informed. There is various literature on adaptation to disability (see for example: Godfrey, Knight, & Partridge, 1996; King, Willoughby, Specht, & Brown, 2006). There is also a diagnostic measure of adjustment to disability (Bell, 1967). However, neither the literature I found nor Bell's *measure of adjustment to disability* address a time frame for adaptation to occur. As a result I enlisted a diagnostic timeframe as partial justification for the six month stipulation. In order to have a diagnosis of chronic pain syndrome a person should have pain that has "persisted for at least 3 months" (Hunt, Silman, Benjamin, McBeth, & Macfarlane, 1999, p. 275). Given this time frame for diagnosis of a chronic condition, it seemed logical to allow at least six months post injury/illness to enable the person to adjust to their new health situation. There is also precedence for utilising a six month timeframe for adjustment to occur amongst other health literature (see for example: Hurel, Loirat, Saulnier, Nicolas, & Brivet, 1997).

Study participants were to be over the age of 18 at date of interview; this was to avoid the need for additional parental consent. Initially it was my intention that participants would have experienced their illness or injury between the ages of 18 and 65 years. My thought process regarding this was the thought that around the age of 18,

men might have had sufficient time to better develop and understand their own view of themselves as men. However further reading on the subject of masculinity has shown that masculinity is a social construct that, some researchers believe, begins as early as in utero (Connell, 2005) and therefore I included potential participants who had experienced their illness/ injury during childhood. Given that the inclusion criteria regarding age of illness/injury were not specified in my research proposal, there was no need to return to the ethics committee for approval to include men who had experienced their illness/injury at a younger age. I felt that utilising 65 as a cut off age for when the person experienced their illness or injury would address any possible age related confounders for the study, for example, reduced abilities due to the natural aging process. For ease of communication, potential participants needed to be able to speak English fluently and be willing to share their experiences with myself as the researcher (Coyne, 1997; Magilvy & Thomas, 2009). As I am based in Dunedin, primary data collection was conducted in this area.

Exclusion criteria included a co-morbid condition present from birth, due to the possibility the co-morbid condition would contribute to the development of the masculine perception of the respondent. A negative psychological state of the respondent at time of contact was also considered a reason for exclusion due to safety concerns and finally a personal connection between the respondent and myself as the researcher was also reason for exclusion (see Figure 3.1).

Participant recruitment.

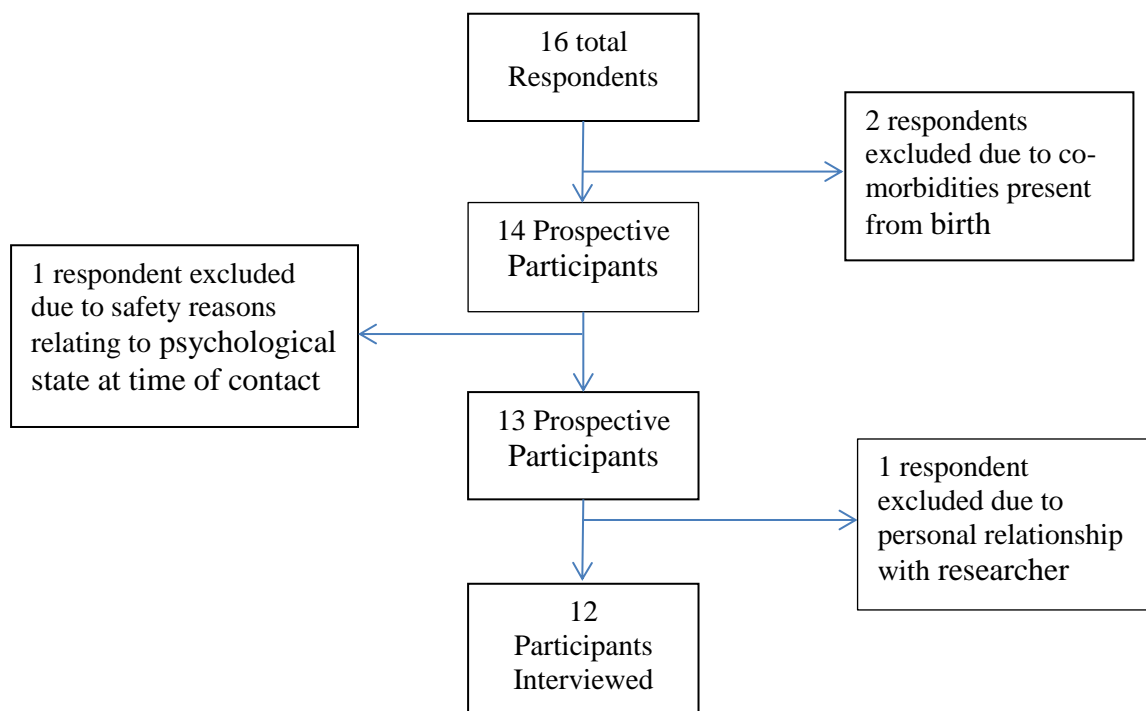
Information regarding the study (see Appendix E), including ethics approval (see Appendix C) and a covering letter (see Appendix F) was posted or hand delivered to several health organisations and practitioners (see Appendix G). I chose these organisations and practitioners either due to my personal knowledge of the practitioner or organisation or suggestion from others. Although initially it was anticipated that follow up letters would be sent approximately 10 days later to those who had not responded to the first letter, I discovered that due to the busy nature of the practitioners, it was best to either speak directly with the clinician or their personal assistant prior to the first mail out, to firstly introduce myself and secondly to notify them of the impending arrival of study information. This negated the need for a second letter to be sent. I had anticipated sending posters (see Appendix H) and information sheets once the clinician agreed to assist in recruitment, however after these discussions, I included

several posters and information sheets which were able to be copied by the clinician within the initial information pack.

With the clinician's or organisation's approval, posters were subsequently placed where potential participants could view them, such as on clinic walls, notice boards and in waiting rooms. Information sheets were given to individual clients whom the practitioner believed may fit the inclusion criteria for the study. Contact details in the form of a University of Canterbury email address and 0800 free call number, which diverted to my personal cell phone, were included for those who had further queries regarding the study. A university email address and 0800 number were used for ease of access for participants and to preserve confidentiality for myself. As I was interested in a range of illnesses and injuries, organisations and practitioners covered broad areas of health related areas such as pain, oncology, general surgery, renal care, mental health, rehabilitation, needs assessment, cardiology, respiratory, rheumatology, HIV/AIDS, general practice, and vision impairment (see Appendix G).

Figure 3.1

Flow Diagram of Research Recruitment



Prospective participants who met the inclusion criteria were invited to become involved in this study through this poster advertising or by direct approach from a clinician or peer. Information sheets and a covering letter (see Appendix I) were emailed or posted to respondents who had not already received an information sheet such as with those who obtained my contact information via a poster. The potential participant was then asked to contact me again once they had reviewed the information to arrange a mutually agreeable time and place for interview if they were interested in being involved in the study.

Data collection.

Within qualitative descriptive studies, data is typically collected through interviews and focus groups (Brown, 2012; Magilvy & Thomas, 2009; Neergaard et al., 2009; Sandelowski, 2000). Focus groups were considered as a method of data collection; however given the personal nature of the information sought, I thought some participants may feel uncomfortable sharing their thoughts and feelings in the presence of their peers. Conducting an interview in a private room, and speaking with myself with no other people around allowed for the privacy of the participant and for the answers to come directly from the participant rather than having input from a third party as could happen when others are present in a focus group (Barriball & While, 1994). I therefore decided that one-on-one interviews would garner the most appropriate information. This decision was justified during data collection as all participants were given the option of having a support person present during their interview and, in the case of two participants, who did elect to have other people present during the interview, the information collected was not as personal in nature as with other interviewees. There are many additional benefits of using semi-structured interviews as a method of data collection.

Semi-structured interviews.

In semi-structured interviews, open-ended questions are asked in order to elicit maximum information and avoid *yes* or *no* answers. Questions beginning with *what*, *how*, *why*, *where*, and *tell me about* will generally evoke some thought and prompt a detailed response from participants and are particularly suited to qualitative description (Kajornboon, 2005; Neergaard et al., 2009; Sandelowski, 2000; Sandelowski, Barroso,

& Voils, 2007). It is important to acknowledge that not all participants will use the same vocabulary and not every word will have the same meaning to each participant. In a semi-structured interview, if participants are unclear about what is being asked, there is an ability for the interviewer to explain or clarify questions by changing words or phrases without adjusting the meaning of these (Barriball & While, 1994). *Validity* and *reliability*, which will be discussed further in the section on trustworthiness, are expressed by equivalence of meaning rather than upon the frequent use of the same words in each question. “It is this equivalence of meaning which helps to standardise the semi-structured interview and facilitate comparability” (Barriball & While, 1994, p. 330). In addition to allowing for adjustment of questions to facilitate understanding, the semi-structured interview format enables researchers to prompt and probe deeper into the given situation, not necessarily using the interview guide, therefore gaining more information (Barriball & While, 1994; Kajornboon, 2005).

Within qualitative semi-structured interviews, the main source of data is the study participant. However within a transactional and subjectivist epistemology, it is recognised that an interview is a two-sided process. That is, the researcher influences the interview process and contributes to the findings along with the participant (Denzin & Lincoln, 2003; Lincoln & Guba, 1985; Lincoln et al., 2011). As the interviewer is essentially the data collection tool, the skills of the interviewer are paramount in gaining full, valid and relevant data. The interviewer needs to be able to take advantage of the structure of the interview process by probing for further information and asking questions that prompt the participant to share more details. As the interviewer, I was constantly aware of the types of questions I was asking, for example, open ended as opposed to double barrelled, closed, multiple or leading questions. I was aware that if I did not provide feedback, probe, prompt or ask open questions at the relevant time, some pertinent data may not have been gathered which would have an effect on the study findings (Barriball & While, 1994; Corbetta, 2003; Kajornboon, 2005; Patton, 1990; Taylor, 2007).

Participants were given the option of meeting in their own homes or in an office at the Dunedin Community House. Seven men elected to meet in their own homes for a variety of reasons relating mainly to comfort and ease of access while a further five met at the Dunedin Community House office. Participants were given the option of being accompanied by a support person and two men took up this offer (see Table 4.1). Each participant was given the option to ask any further questions regarding the study prior

to the interview commencing and verbal and written informed consent for the interview, audiotaping and note taking was gained prior to the interview (see Appendix J). I was conscious that participants' responses to questions could be influenced by perceptions of the role and status of the interviewer (Taylor, 2007) so, in preparation for the interview I dressed in casual, but appropriate, attire to avoid any perception of hierarchy within the interview and potential biasing due to this. To an outside observer the interview would have resembled a general conversation between equals. Water was made available for interviews conducted at Dunedin Community House, and participants were advised of their right to stop the interview at any stage. There was a possibility that during the interview and analysis process, themes might have emerged that were not addressed with initial study questions so participants were also asked if they could be contacted if necessary for a secondary interview, either face-to-face, or by follow up phone call or email to address these or for clarification of information. However further contact was not required as participants provided me with more than enough information to answer the study questions and there was nothing unusual in the analysis that required follow-up.

The construction of an effective research tool, in this case a semi-structured interview guide is paramount to the study success (see Appendix K). In order to effectively carry out a study it is important to develop a questionnaire that addresses the research questions (Bloomberg & Volpe, 2012). Each interview question should directly relate to the research question and purpose of the study in some way (see Table 3.2). In addition to answering the research question, I wanted to know about the men I was interviewing. This was achieved by using a survey format to ask participants for specific demographic information regarding, age, ethnicity, type of injury/ illness, and length of time the participant had been living with the effects of their particular injury/ illness at the beginning of the interviews (see Table 4.1). This demographic information will be presented in Chapter Four. I also wanted establish if there was a difference before and after injury/illness in the lives of these men and then find out about their self-perceptions of masculinity before their illness or injury and to establish if these perceptions had changed subsequent to the illness or disability. In order to answer these questions, a semi structured interview guide was constructed with nine questions and some additional prompts (see Table 3.1).

Table 3.1

Justification of Interview Questions

<u>Interview Question</u>	<u>Why was this question asked?</u>
<i>Question One:</i> Tell me what life was like for you prior to your accident (or illness)?	Baseline of what the participant's life was like before his illness/ injury.
<i>Question Two:</i> What did being masculine mean to you then?	To find out about the participant's self-perceptions of masculinity before his illness or injury.
<i>Question Three:</i> What kind of things did you do? <ul style="list-style-type: none"> • In your family life? Time with children, partner, jobs around the home... • Work life – Were you employed? What did you do? Did you work full time? • What did you do in your social life? With your friends? • What hobbies/ sports were you involved in? 	To provide a baseline of what the participant's life was like before his illness/ injury and to investigate how he saw these aspects of his life with a focus on how that relates to a masculine context.
<i>Question Four:</i> Tell me about your injury/ illness.	To provide context and understanding of the participant's individual situation.
<i>Question Five:</i> What was it like for you?	To elicit some memory regarding the processes around this time.
<i>Question Six:</i> How did this affect your life?	To elicit some memory regarding the processes around this time and to establish if there was a difference before and after injury/illness in the lives of the participants.
<i>Question Seven:</i> How did things change for you? <ul style="list-style-type: none"> • In your family life? Time with children, partner, jobs around the home... • Work life -employment? What do you do now? • What do you do in your social life? With your friends? • What hobbies/ sports are you involved in? 	To establish if there was a difference before and after injury/illness in the lives of the participants and to find out about the participant's self-perceptions of masculinity after their illness or injury and to establish if these perceptions had changed subsequent to the illness or disability.

<u>Interview Question</u>	<u>Why was this question asked?</u>
<i>Question Eight:</i> How did this affect your view of yourself as masculine/ as a man?	To find out about the participant's self-perceptions of masculinity after his illness or injury and to establish if these perceptions had changed subsequent to the illness or disability.
<i>Question Nine:</i> Is there anything that we haven't talked about that you would like to add?	To ensure there is no further information that was not covered in the interview that the participant wanted to share. To terminate the interview.

It was assumed that interviews would last approximately one hour each, although there was no time limit placed as I was happy for participants to take as long as required to feel they had shared as much information as they felt comfortable with. Data were gathered between the first week of September 2012 and the first week of April 2013. Recruitment took much longer than expected, possibly in part due to the Christmas/ New Year holiday period. Interviews ranged from 25 – 104 minutes in duration with an average length of 64 minutes. All interviews were digitally recorded and then transcribed verbatim either by myself or by a professional transcriber who had signed a confidentiality agreement (see Appendix L). I had intended to transcribe as many interviews as possible in order to both reduce costs and become more immersed in the data, however given the time it took me to transcribe was extensive, it became apparent that if I was to finish transcription a professional would need to be engaged.

Confidentiality.

Once transcribed, participants' data were anonymised using identification numbers in order to ensure confidentiality in accordance with the principles of the New Zealand Privacy Act 1993 (New Zealand Government, 1993). One participant is well-known in the media and due to the unusual nature of his illness/injury; I was unsure if I would be able to guarantee his anonymity. This was discussed with the participant and although I assured him all practicable steps would be taken, he was happy if his anonymity was not fully preserved.

Digital files were created for each participant. These files contained an electronic copy of the interview transcript and the digital recording of the interview. The digital recordings will be destroyed upon completion of the study, while the transcripts and consent forms will be retained for a further five years in accordance with University of Canterbury policy, then destroyed. The digital files are stored on my personal password protected laptop. Hard copies of the interviews are stored along with

transcriber confidentiality forms, consent forms and other study material in a locked drawer, only accessible by me.

Data analysis.

Data analysis is divided into three, sometimes overlapping, phases: preparation, analysis (also known as organising) and reporting (also known as interpretation) (Elo & Kyngäs, 2008; Sandelowski, 1995a). There are various methods of data analysis, which include, but are not limited to, phenomenological analysis, grounded theory analysis, discourse analysis and content analysis (Hsieh & Shannon, 2005; D. R. Thomas, 2006). Typically qualitative content analysis is utilised for data analysis within qualitative descriptive studies (Neergaard et al., 2009; Sandelowski, 2000). There are various forms of content analysis. Hsieh and Shannon (2005) focused on three of these forms, and defined them as conventional, directed content, and summative. Elo and Kyngäs (2008) described how content analysis can be used in either an inductive or deductive manner. Within naturalistic inquiry, data analysis is seen to be inductive and open-ended (Lincoln & Guba, 1985). Inductive analysis allows themes to emerge from the data without imposing the restraints found in more structured forms of analysis (D. R. Thomas, 2006). This approach to data analysis is consistent with a qualitative descriptive methodology. Both inductive and conventional content analysis are utilised when there is limited knowledge in an area of study (Hsieh & Shannon, 2005; D. R. Thomas, 2006). As such, a general inductive approach to content analysis was undertaken to identify the key themes arising from the data.

Preparation.

After the interviews were transcribed, the transcripts were reviewed alongside the recording to ensure accuracy. I then re-read each transcript while again listening to the digital recordings and removed any non-relevant information from the written transcript, such as general conversation, and changed the interviews into a standard format for ease of reading; this process is known as *data cleaning* (D. R. Thomas, 2006). During the data cleaning phase, I marked segments of text which had similar content to other interview segments. This is an example of where data preparation can overlap into the data analysis phase (Sandelowski, 1995a).

Analysis.

I began my data analysis by reading the data cleaned transcripts through several times. I made notes in the margins regarding the topics the participants were discussing. Magilvy and Thomas (2009), found that through the process of “reading, re-reading data, listening to audio recordings, reviewing field notes, maybe clarifying with participants what we are learning, the analysis and findings reveal themselves to us in the form of categories, patterns and themes” (p. 299). The word *coding* is used in similar but varying capacity amongst the literature. Additionally the terms *categories*, *patterns* and *themes* are often used interchangeably. Elo and Kyngäs (2008) identify coding as the process of writing notes and headings on the text while it is being read. Magilvy and Thomas (2009), discuss the process of *coding* as finding words and phrases which are repeated throughout the interviews. These *codes* are then grouped into *categories* of similar words and phrases; *categories* with common topics are then grouped together into *themes*. D. R. Thomas (2006) describes the process of *coding* as looking for common *patterns* and *themes* within the data and assigning a *category* to these. The word *category* is utilised at each step of the process; larger numbers of initial *categories* are combined into a smaller number of *categories* until the number reaches between three and eight total *categories*. For the purpose of this study I will be primarily deferring to D. R. Thomas (2006) and will continue to describe each step I undertook within the analysis phase.

Some of the participants had volunteered so much information, that they had covered most, if not all, of the information sought in the interview guide without me having to ask many questions. While there was a wealth of information, much of it did not follow a chronological order. I initially found it difficult to make sense of the many pages of transcripts so I started by separating the information into three groups: Before injury/illness, during acute phase and description of injury/illness, and post injury/illness and current situation. As discussed in the previous section on data collection, each of the interview questions and its prompts were designed to gain information relating to sections of my research. In order to show whether there was a difference in participants’ lives I first gathered data into sub areas of employment, leisure and family. The decision for these groupings was primarily due to the way the interview guide was structured. By describing these aspects of the participants’ lives I was able to establish that there was a difference before and after illness and injury.

I then went back to each group and re-read the transcripts. There was less data in the first two groups which was to be expected given the main focus of the interviews was the participants' stories after their illness/injury. I started with the pre-injury group and looked for common patterns and themes and then grouped them into categories. Some of the categories were very small, so I combined them with others of similar content. Within inductive content analysis it was up to me as the researcher to make the often difficult decisions regarding which categories and themes were most important and were to remain included in the findings (Starks & Trinidad, 2007; D. R. Thomas, 2006). Information regarding the actual mode or illness/injury was kept with the demographic data.

In the group of data relating to post injury/illness, I initially maintained the three sub areas of employment, leisure and family. However it soon became clear that similar stories were being told in each area. For example, some participants had family who were very supportive, but had friends who stopped visiting or making contact. Some participants experienced their friends being supportive but their family staying away and others had a mixture of these. The main theme running through these areas was the change in relationships, with friends, wives/ partners, children and extended family, which was experienced due to the illness/injury. Additionally what constituted employment and leisure activities had changed post injury/ illness. This meant that what previously had neatly fit into one category now spanned several. Much of the data crossed into more than one category. For example, themes of loss and dependence were apparent in all areas of the participants' lives, however along with these were the contrasting themes of gain and independence. In qualitative description, themes emerge from the data (Magilvy & Thomas, 2009; Sandelowski, 2000). As such I did not try to put the data into preconceived categories. This meant that categories emerged that were different to those I would have expected given the literature review. Although some of the topics were consistent with the literature review topics and the groupings from the pre injury/ illness data, the data post injury/ illness seemed mostly to naturally fall into different categories. The comparison of these will be discussed in Chapter Five.

Once all of the themes that had arisen from the literature had been addressed, which was achieved by examining the significance of what the participants had said, recognising connections between the coded information and "reflecting on the overall importance of [the] findings for the research question and the research literature that

[had] driven [my] data collection” (Bryman, 2004, p. 409), the findings were written up for review.

Reporting.

Within qualitative descriptive studies, findings are reported using the participants own words and language which has similarity to these (Neergaard et al., 2009). The use of quotes reinforces the analysis undertaken (D. R. Thomas, 2006). The result is a descriptive summary of the data arranged in a manner which “best fits the data” (Sandelowski, 2000, p. 339). The findings of the data analysis are found in Chapter Four.

Issues of trustworthiness.

The issue of quality or academic rigour has been a concern in qualitative studies for many years (Rolfe, 2006). A consensus on what is determined to be good, valid and reliable research is difficult to establish given the wide range of qualitative methodologies (Rolfe, 2006; Sandelowski & Barroso, 2002). Validity and reliability are terms most commonly associated with quantitative research (E. Thomas & Magilvy, 2011). Lincoln and Guba (1985) discussed the validity and reliability of qualitative studies in terms of *trustworthiness*, which is the ways in which an “inquirer [can] persuade his or her audiences (including self) that the findings and inquiry are worth paying attention to, worth taking account of” (p. 290). Trustworthiness is described as consisting of four components – credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985; Rolfe, 2006; E. Thomas & Magilvy, 2011).

Credibility is comparative to internal validity in quantitative research (Rolfe, 2006; E. Thomas & Magilvy, 2011). Credibility is achieved when a description of the data is presented which is recognised as accurate by those who have experienced the same phenomenon (Lincoln & Guba, 1985; E. Thomas & Magilvy, 2011). In order to address trustworthiness in this study, interviews were digitally recorded and transcribed verbatim to ensure credibility. Digital recording of interviews “reduces the potential for interviewer error by, for example, recording data incorrectly or cheating by logging an answer to a question that was not asked” (Barriball & While, 1994, p. 332). In addition to the recording, extra information in the form of notes were taken by the interviewer regarding two participants. These notes were a brief outline of discussions that took place once the dictaphone had been turned off and were points these two participants

raised as an afterthought as I was leaving the place of interview. The other participants did not raise any extra points once the interview was terminated negating the need for notes to be taken. The recordings, transcripts and notes provided an opportunity to compare the findings of the study against the ‘raw data’. Although none of the participants took up the offer, participants were given the opportunity to review the interview transcript for accuracy; Lincoln and Guba (1985) defined this process as *member checking*.

Another method of achieving credibility is *peer debriefing*. Although I did not engage in peer debriefing as specifically defined by Lincoln and Guba (1985), where the peer is neither junior nor senior to myself, I did engage in debriefing both with my supervisors and other people in the academic arena. This debriefing allowed me to work through issues of writers block, and various ideas relating to both the thesis construction and content and gain invaluable feedback on these. In addition, although I kept some hand written notes about ideas raised during these sessions, the notes were not kept in the format of an audit trail.

Transferability refers to the generalisability of the findings to other subject areas (Guba, 1981). This was achieved through purposeful sampling, by selecting potential participants in this manner the researcher ensures they are “providing sufficient descriptive data” (Lincoln & Guba, 1985, p. 298) to allow others to make judgements of similarity in research. By using a semi-structured interview, I could, as the researcher, probe deeper into any given situation, while not necessarily using the interview guide, therefore gaining more information. Given the need for knowledge in both “transferring and receiving contexts” (Guba, 1981, p. 81), it is up to the reader to determine the relevance of the findings to their own situation. As the researcher, I have attempted to facilitate this by providing a *thick* description of the research and its context in the first three chapters of this thesis.

Adjusting interviews and rephrasing questions while maintaining “sufficient standardisation to secure the validity and reliability of data” (Moser & Kalton, 1986 as cited in Barriball & While, 1994, p. 333) was key to the *dependability* of this study. Within a constructivist paradigm, multiple realities are observed. The role of the researcher as an instrument of the research is acknowledged, along with the reality that these instruments are subject to change (Guba, 1981). As such the naturalist inquirer is not as concerned whether research can be repeated with an exact outcome, rather their interest lies in the ability to “track the processes and procedures used to collect and

interpret the data” (Bloomberg & Volpe, 2012, p. 113). This was achieved by providing a comprehensive methods section.

Confirmability is comparable to the concept of objectivity in quantitative research (Guba, 1981). Given the impossible task of complete neutrality within naturalistic inquiry, a constructive paradigm instead acknowledges the biases the researcher may bring to the findings. Confirmability is achieved by ensuring transparency by systematically documenting the process of the study along with presenting the data in an objective manner. Reflexivity is another manner in which confirmability can be achieved. This is the process of identifying and revealing the biases and underlying assumptions that the researcher may bring to the study (Bloomberg & Volpe, 2012; Guba, 1981). Peer and academic supervision have been invaluable in assisting in identifying and addressing my own values and beliefs and being consciously aware of these while conducting the data collection and analysis of this study.

Summary

Within the first three chapters of this thesis, I have provided an introduction and background to the research. As a part of the research background a literature review was conducted which informed the study I undertook. In this third chapter, I have addressed the research methodology along with providing a comprehensive description of the methods I undertook in conducting this study, and the ethical implications and issues of trustworthiness associated with these. In the following two chapters I will present and provide a discussion of my findings and will address the strengths and limitations of the study and make suggestions for further research and practice.

Chapter 4 - Findings

In this chapter I present the findings that emerged from the research data. I have divided this chapter into three sections. In the first section I describe the participants involved in the study and their lives both before and after injury/illness. The information gained in this section came from a survey of demographic questions as well as from the interview transcripts and provided an answer to the question of whether participants experienced difference in their lives after their injury/illness. The second section is the findings arising from the information gained about what participants thought it was to be a man or masculine before they experienced their illness/ injury and provided a comparison for the analysis. The final section is the findings arising from the data regarding how participants experienced their injury/illness in relation to their view of being a man or masculine and is the primary focus of this study. Despite the differences in injury, illness or age affected, the stories that were told throughout the interviews had many common themes. These themes were explored under the categories of: Men are defined by what they do: coping with occupational changes; the frustration of being dependent, eventual acceptance and moving on; relationships change – some people just can't cope; and loss and change.

Demographic Data

Twelve men between the ages of 39 and 64 with an average age of 52.75 were interviewed in the location of their choice. One of the men identified as New Zealand Māori, one had Māori heritage but identified as European and the remaining 10 men described themselves as a combination of Kiwi/European/ Pākehā/ New Zealander/ Caucasian. A range of illnesses and injuries were represented. The time living with the effects of injury or illness ranged from 15 months to 45 years with an average duration of 17.6 years. Two of the men contracted their illness or were injured before the age of 18, while the remainder were injured or became unwell after the age of 18.

Table 4.1*Demographic Data of Study Participants*

<u>Participant</u>	<u>Injury/Illness</u>	<u>Duration</u>	<u>Interview location</u>	<u>Accompanied</u>
P1	Locked in Syndrome due to rugby injury	12 years	Home	Yes (Partner and Caregiver)
P2	Chemically Induced Injury (work related)	22 years	Office	No
P3	Angina Physical injuries to wrists and face due to a fall and Meniere's Disease	12 years 4 years	Office	No
P4	Incomplete Tetraplegia due to tumour C4-T6	16 years	Home	Yes (Wife)
P5	Stroke	6 years	Home	No
P6	Knee Injury due to rugby	35 Years	Office	No
P7	Right Side Hemiplegia from Meningitis	20Years	Home	No
P8	T5 Incomplete Paraplegic due to accidental fall	45 Years	Office	No
P9	Parkinson's/ Back Injury from work	15 months	Home	No
P10	C4/5 Incomplete Tetraplegia due to rugby injury	26 Years	Office	No
P11	Chronic Pain arising from restless leg syndrome	14 years	Home	Wife in home but not present for interview
P12	Severe Chronic Heart Failure	3 years	Home	No

Employment.***Before injury/ illness.***

Prior to experiencing disability due to their illness or injuries, study participants all reported having very busy, active, physical and full lives. Employment took up a majority of time with participants reporting between 60 and 70 hours per week spent in

paid or sometimes unpaid work. Two participants were of school age when they became injured/ unwell. One of these also worked part time on the family farm out of school hours. One participant was studying full time at tertiary level, having just left a full time position which he continued on a part time basis while studying. The remaining nine participants all had full time jobs and of these, four were engaged in additional part time employment. There was a mixture of blue and white collar work with employments including printer, draughtsman, pastor, IT/ administration, linesman, ambulance officer, property manager/maintenance, roofer, car groomer, insurance agent/ financial planner, foreman, greens keeper and motel operator.

After injury/ illness.

One of the participants who had his illness/ injury prior to age 18 had to give up his dream of becoming a fireman or policeman. He works in a casual capacity when his disability allows and is primarily dependant on his partner for financial support. The other did not have any firm ideas on a future employment at the time of his disability and is employed in a position where his disability is not a limiting factor. Two participants have undertaken altered roles within their previous workplace. The remaining participants had to leave their pre-illness/ injury employment due to their resulting disabilities. Of these, four receive weekly compensation from ACC, two are in receipt of WINZ benefits, one has income from investments and one is solely reliant on his wife for financial support.

Leisure.

Before injury/ illness.

Leisure activities prior to illness/ injury were similar regardless of age and focused a lot on physical and socialisation activities along with a small number of individual activities. Physical activities included going to the gym, playing and watching sports such as rugby, soccer, cricket, squash, bowls, biking, swimming, tramping, running, golf, fishing, hunting, and ballroom dancing. Social clubs such as church social group, car club, four wheel drive club, motorcycle club, bowling club along with various sporting clubs provided additional centres for socialisation along with dinner parties and going to pubs. Individual activities included working on cars and/or motorcycles (although this was also done with friends) and one participant reported a minimal amount of reading. Eight of the 12 participants had young children who they included

in an energetic lifestyle with activities such as roller skating, ice skating, basketball, canoeing, fishing and kicking a ball around at a park.

After injury/ illness.

As with the area of employment, leisure activities which participants engaged in also have undergone a substantial change due to the revised physical capacity of each participant. Although physical activities still feature, the type and amount of activities differ. Sports that incorporate disabilities such as those seen at Paralympic events were mentioned, although the cost in being involved in these forms of sports was a limitation to involvement to most. One participant reported being involved with karate and table tennis while another plays boccia. In some cases modified equipment and technique have allowed participants to continue in some sporting activities such as fishing, cycling or swimming. Attending the gym and swimming are significant physical activities that most participants engage in, however these activities have altered in role from being leisure pursuits prior to injury to taking on an employment role post injury as physical fitness is an important self-care activity. The social aspect of participants' lives have also changed; although some participants still attend sporting club rooms such as bowls or rugby, they do so for a much shorter time period and do not consume alcohol while there. Social media outlets such as Facebook, Twitter or Yahoo chat also provide space for socialisation. The social circle of the participants has also undergone a change and in most cases has decreased. Individual leisure activities have increased post injury/ illness. Reading books and watching television feature significantly along with computing and making items such as radio controlled planes and other models.

Family.

Before injury/ illness.

Two participants were under the age of 18 at the time of their injury or illness. These two participants had two parent families and siblings. Eight of the 12 participants had children of their own. Five participants were in married relationships and two participants had girlfriends. Family life involved home renovations, doing other manual chores around the house and spending time with family members such as wives and children, often doing activities such as those listed above.

After injury/ illness.

Participants reported relationship changes in part due to their illness/ injury and in part due to the natural processes of aging. The two participants who had their illness/ injury prior to age 18 have both left the family home and are currently in married relationships. One of these has children who have grown and left the family home. Three participants have remained married or in a relationship with the same person as they were prior to their illness or injury. Four are in new married or defacto relationships and one is single. Participants have taken on more of the caring roles in the family by taking family members to appointments, looking after children and completing most of the household work. Spending time with family members is still a part of family life although the types of activities engaged in have changed and now mostly consists of going to cafes and watching children play on playgrounds.

What Does It Mean To Be A Man? – Thinking Back To Before Illness/ Injury

Participants defined themselves as men in terms of masculine ideals. The concept of being a man and being masculine were considered one in the same. Opinions regarding masculine ideals were similar between participants. The participants described what being a man/ masculine meant to them before their injuries or illnesses.

Sports, socialising and being competitive.

The word masculine was also defined as manly or macho; these terms were used interchangeably and were described as being involved in sports especially rugby and other physical activities; having an interest in cars and/ or motorcycles; partying and drinking alcohol – often to excess; socialising with mates at the pub or while doing activities such as those listed above. The socialising, competitive nature of being a man, and the need to be better than others along with the *mateship* or *camaraderie* that came from these social events was a significant theme in life prior to injury/ illness as explained by participant ten:

Well just the things you do with your mates, the comradeship, you know, just your team spirit and things that are pretty much like that you know. Just competition, and beating, and revving people, and that kind of fun. Yeah, socialising, a lot of socialising....just being physical and competitive and

wanting to beat the opposition, beat the other person or the other – you know. Not maliciously or... just, but seriously. Dig them playing rugby and it's very competitive (P10).

Providing and contributing to the family.

Taking responsibility, particularly in the home sphere by being a good provider for the family and role model for children featured highly for participants with children; *“It was very important to me to be a role model to those kids” (P3)*. Looking after, providing for and having money to pay for items for wives and children was also a vital part of being a man as articulated by participant nine: *“I always had money for the kids and I'd shout them things, and you know buy them things, and contributing to the family which was really, really good” (P9)*. Although many of the men reiterated these beliefs, Participant eleven was most succinct in saying:

Yeah that was important to me, providing for my family, it always was. Making sure my son had everything that he wanted that I didn't have growing up, making sure my wife was looked after that best that I could. Yeah, those sorts of things are very important, yeah (P11).

Working and being occupied outside the home.

Participants also defined themselves as men by the location and type of work they did. There was a belief among participants that men work outside the home, whether this was in paid employment or around the house. Participant three talked about his grandfather, whom he saw as the epitome of a ‘real man’, as a man who *“always liked to be someone working outside the home and was hardly in...even after he was retired he was working in the garden” (P3)*. Although some men talked about helping their wives/ partners around the house, they were also clear in the fact that domestic chores were not their primary domain, as participant five states his role in the family home was *“being more of a provider than a homemaker” (P5)*.

Fathering and modelling other masculine traits.

Along with providing financially for their children, being a good father involved taking an interest in children's activities, spending quality time with children and building their confidence particularly through physical activities. Modelling masculine

behaviours was also a part of being a good father. Some of the key masculine behaviours that were considered valuable to pass on to children were: being a good friend and being there for others; standing up for principles, self and friends; fighting for beliefs and rights for self, family and friends, physical fighting with other males in certain cases, but not hitting women/girls; being reliable, straightforward and saying what you think and keeping your word. When asked about what behaviours he thought were important to model to his young son, participant three said:

...particularly thinking about their growth and so on, keeping your word, being straightforward about things you like or disliked – you know...tell people what you thought about things, and um, standing up for your own principles that you've learned and those would be the sort of main things I suppose (P3).

Another masculine ideal voiced by many participants was being independent. Participants talked about being autonomous in their lives. Independence could also sometimes be construed as being stubborn. It was important for participants to be the person 'in charge'. Masculine men were also seen as organisers and the one to take control in any situation. Appearance was also important, to be attractive and attracted to the opposite sex and *"having nice looking girlfriends"* (P1).

Life is Different Now – Analysis of Life Post Injury or Illness

Men are defined by what they do - Coping with occupational changes.

What constituted employment and leisure activities had changed in definition and in many cases was adjusted to fit the masculine identity of the participant. Participants continued to describe their lives as busy although they recognised the amount of activities they undertook were significantly less in comparison to their lives prior to injury/ illness. Being identified as involved in some form of work that contributed to society was important to participants; this was talked about in terms of helping others.

One of the latest parts of it, of helping is I've arranged to donate my body to the medical school when I die. So hopefully they can dig around and find something in there that might be able to help somebody else (P4).

Many participants were currently involved in education both formal and informal; giving information and describing their own experiences of a particular illness/ injury or disability was a common occupation amongst participants:

Another thing I do is talk to med students at varsity. I do several sessions with them, just talking about life with a disability type thing. So that's a bit of voluntary work I suppose you could say. Mind you they pay you in food stamps (P10).

Although this work is seen as helping others there is also sometimes an element of personal benefit as explained by participant four:

[volunteering for students is] in my favour, because the way I look at it, one day one of these people might be looking after me so I don't mind spending time letting them use me as a training person (P4).

Sharing ones' own experience with others in a similar situation is another form of helping. Participant ten talked about providing an informal support network by:

help[ing] others transition from [before injury to injured], in an informal way. Visiting and catching up and keeping in touch with other tetraplegics around Otago/Southland and right throughout New Zealand (P10).

Other volunteer work such as driving people to appointments for the blind foundation, being involved in disability and advocacy groups along with sitting on various committees was also seen as a way to contribute to society that participants engage in.

Regardless of financial income, participants often discussed their daily occupations in terms of work. Several participants talked about managing their own lives as being an important part of their daily tasks. This involves organising caregiver wages and rosters, planning meals and errands, along with swimming and engaging in gym work, which as previously stated had been considered leisure pursuits, are now considered an important occupation in managing the participants' own health.

I wouldn't have time for a full time job in my life really on top of keeping healthy as much as I can and keeping fit, it just takes longer to do things... It's planning and organising those things takes time, a huge amount of time. Yeah managing my life takes a lot of time (P10).

Some participants looked at their employment status as an acceleration of the natural process with one stating: *"I always wanted to retire when I was fifty and I just retired when I was twenty eight, that's early"* (P10). Regardless of how they filled the hours in their day, all of the participants voiced the importance of being occupied in a manner that was meaningful to them and contributed in some way either to their own lives or the lives of others, as participant ten says: *"Managing my life has got meaning, it's got purpose, yeah"* (P10).

Along with work activities, participants have also changed their leisure activities to suit their personal situations. Along with substituting one form of occupation for another, adjusting how an activity is completed is another way to remain occupied. Participant six talks about completing a sporting event as part of a team rather than individually:

I did the coast to coast a couple of years ago in a team. I knew that I couldn't run up over the hill but I biked a fair part of the way and I kayaked the rest so in that sense I was holding up my end with the challenge... I'd like to be able to do it on my own but yeah the injury just won't let me do it (P6).

Another participant negotiated with organisers to be still able to attend motorcycle rallies by travelling in a van rather than on a motorcycle. Picking and choosing where to do activities, is another method of adjustment, for example fishing at a lakeside or off a boat rather than on rivers or where there is difficult access.

Being proud of what you do - Self-esteem and occupation.

Self-esteem is intertwined with a meaningful occupation and the perceived value others place on participants' work: *"To have people phone me up or send emails and thank me for an enjoyable article or actually want to meet me... suddenly the self-esteem and the confidence that I used to have has started to come back"* (P2).

Participants talked about the value they felt when others, particularly employers, made concessions and tried to work around their disability. When talking about being offered alternative work within the same organisation participant twelve said:

I felt quite proud cause I had done such a good job, like building a morale thing around someone it was very good, I felt really great, I said yes I wouldn't mind, worked there for another year and then they say we got another job here would you mind taking it over (P12).

Working around reduced hours and providing equipment to enable participation also contributed to the self-esteem and value a participant experienced post injury/illness. Participant twelve discusses the effort a community organisation went to in order to allow him to continue with a volunteer position:

They got an automatic caller, so it was all a computer voice, so you just have to not call, push the buttons to call the housie. At that time it cost them almost two grand to buy the computer and all the equipment associated with it. So they looked after me there, it was quite impressive. So I would work there and do less there... so I would do two nights out of five or six. I was doing every night before (P12).

Being occupied in a meaningful way whether there is financial reward or not is paramount to the self-esteem a participant experienced, as participant two explains: *There was nothing finer than people saying what do you do? And being able to put a business card in their hands (P2).*

The frustration of being dependent, eventual acceptance and moving on.

Being dependant on others and the frustration, and in some cases eventual acceptance, felt due to dependence is a significant theme throughout the interviews. This theme of dependence fell into three areas of financial, institutional, and physical and psychological dependence.

Financial dependence - No longer being a good provider.

Contributing to the family is an important theme for participants. Participants report taking on primary responsibility for domestic duties in lieu of financial contribution to the family. Difficulty is experienced when reconciling their current home role with not being the breadwinner of the family. As participant seven says:

It's kind of one or the other, you're either earning money to contribute financially or you contribute by doing stuff around the house. But you can't do both and neither are enough... I'm technically the wife... because [wife] is the main breadwinner and away most of the time. I probably do 80% of the housework (P7).

Being dependant on a partner for financial support is problematic for many of the participants. Two of the participants are dependent on their wives for financial support as their wives earn an amount higher than the threshold for government support. Both of these men discussed the thought of dissolving their relationships as they feel they a financial burden on their partners:

You wake up in the early hours of the morning or you know you've got negative thoughts, wondering if you'd be better off getting into a flat. And I've discussed it a few times with her [wife] on a few occasions and living by myself because I'm not doing anyone any favours by living here. Living off one wage that my partner earns, because she's the only one that works, and you get on a bit of a downer and it happens quite often... Yeah, but I feel that if I done that, I would feel really upset because I've got my dogs and my family life is really good and my partner is great and the kids are great (P9).

The participants' need to contribute financially to the family often overrides the need to care for themselves. The stress and physical exhaustion that comes from in some cases the smallest amount of paid employment can be detrimental to both the relationships of the participants as well as their own well-being. As participant seven says: “*yeah cause we don't get any quality time together, very little quality time and when we do we're both too knackered to do anything*” (P7).

The difficulty experienced in working to a pace that is conducive to their disability is reiterated by participants eleven and four:

I try and work in a window of two hours. My clinical psychologist has tried to get me to recognise that if I'm going to do something around the place, to do it in a set time frame and no more so I don't play things out. And I am hopeless at that, absolutely hopeless at that (P11).

For what I do I seem to end up pretty busy. I get growled at every now and then by the OT when she comes over and sees me (P4).

The guilt felt about not contributing to the family income also means some participants do not engage in occupations that require them to use any money: *"I didn't want to use the money card to put petrol in the car so I could go for a drive. That's how bad I feel about it (P9).* When talking about no longer being able to continue in paid employment participant two said:

It was devastating because I'd always worked hard and long and I thought I was a good provider and suddenly your self-esteem just goes on the floor. I just became quite reclusive and my wife would say oh lets go out and I'd make all sorts of excuses as to why I didn't want to go out but basically I couldn't face looking at people in the eye and say – when they ask you the ultimate question oh – what do you do? What do you do for a living? What's your job? You say I've got no job (P2).

Institutional dependence - Being degraded by the process and people.

Financial dependence on organisations such as Accident Compensation Corporation (ACC) and Work and Income New Zealand (WINZ) for financial support has its own set of problems. Not working and being reliant on a government benefit is described as demoralising and a source of embarrassment for some participants. Participants reported struggling financially and not asking for extra assistance because of the associated stigma:

I hated it I really do. I mean I've heard of people going through Pak n Save with a food voucher and the teller has said "oh no you can't have that, you can't have that in your trolley" and it was ice-cream and stuff like that (P11).

The feeling of being in the public eye while in receipt of a benefit is prominent "...and the way they've got WINZ set up now of course there's no privacy when you go in there" (P11). One participant spoke about watching his father get caught in a downward spiral of depression and eventual suicide after losing his job and having to live on an unemployment benefit. The father felt so degraded by the experience of going into the unemployment office that eventually he refused to attend appointments so his wife would drop off any paperwork that was required. Some participants report that they feel so judged by neighbours and friends about their level of disability and entitlement to receive financial support that it has resulted in additional social isolation. Participant eleven shares:

I've worked with people in the past where it's discussed, you know, things about people scamming ACC and all those sort of things, and you just think well are people watching me and thinking of me in the same category now (P11).

Participants who have been previously in paid employment also reported feeling unfamiliar with benefit systems and powerless when dealing with agencies providing financial support:

So I had been working for a long part of my life and then to no longer be a provider and then you go through the mill of WINZ and that's just a roller coaster ride. I mean you don't know from day to day whether you're going to get a letter in the post that says you've got to come in for this, or this payments been stopped now, or - we've got a good case manager now but at the end of the day you just never know what's going to happen there. So to be a breadwinner again would be good, not to have that hassle (P11).

Agency staff who make decisions on eligibility for financial assistance are reliant on medical reports for information regarding the employment capabilities of

their client. Participants report staff often do not take on board the meaning of these reports and as a result participants feel pushed into employment and tasks that were unsuitable and in some cases detrimental to their on-going health. In some cases participants reported they were also not aware of or capable of understanding their situation fully as one participant describes:

I went back to the [specialist] and he just shook his head and said “no way”, he said “under no circumstances should you ever have been able to go back to that type of work.” He said “did nobody advise you against it?” I said “no, nobody did.” He said “oh, it’s all well and good saying you should have but... had you made one phone call to me I would have steam rolled it” (P2).

Dealing with agency procedures can take up a lot of time and energy that participants do not have as participant two describes: *“The first 18 years of being on ACC required about 15-20 hours a week of hard labour, sitting at a typewriter, sitting at a computer keyboard, knocking off correspondence” (P2).* The financial and emotional cost of these procedures was also discussed:

...and I went onto the sickness benefit and had to go get medical certificates and that costs you and you know...It was demeaning, but it’s so hard because you can’t... that’s where the benefit is wrong because people get isolated they hunch over, they can’t get a job (P12).

There is a clear frustration amongst participants at having to deal with the often foreign policy and procedural practices of institutions who are providing financial support:

You have no idea when you start the journey with ACC just what you’ve let yourself in for. Because they have the right under law to investigate to any lengths they consider necessary. Even though my medical certificate states that my condition is serious and permanent and non-recoverable, I’ve had to provide them with 65 medical reports in a 22 year period. Even some of the doctors that I’ve been to have written to ACC and said “what is so hard to

comprehend with this subject, he has a permanent condition that is not going to get better". I've accepted that why can't they? (P2).

Health professionals should know what is wrong - Why should I have to tell them?

Along with institutions that deal with financial assistance, dependence on health care providers was a recurring theme in the stories participants told. Many participants talked about their assumption that health professionals have expertise in all medical areas, the perceptions that doctors would be able to 'fix' them and the frustration they felt when it was realised this was not the case.

I've been going to appointments with the medical school or the Dunedin Hospital and senior-senior doctors have looked at my file and said "oh what on earth is chronic solvent neurotoxicity? How do you get that?" So you have to explain again (P2).

As with institutions such as WINZ and ACC, participants voiced frustration and a lack of understanding regarding institutional practices and policies when it comes to health care organisations. The lack of communication between health professionals is a cause for concern and stress. One participant voiced a need for a central coordinating person to keep track of appointments and for health professionals to talk to each other rather than working individually, not knowing what other providers were doing. Although privacy was a recognised concern the participant voiced a willingness to sign consent forms for each healthcare professional to allow them to discuss his on-going treatment.

The lack of understanding about how to talk about their disability in medical terms is also a factor. Participants often undersell the difficulty they experience in their daily life because they do not want to appear weak. In addition, there is an expectation that the doctors will be able to see through this bravado and understand the difficulties regardless of what is actually said. By providing an appropriate diagnosis the doctor then provides a legitimate reason for the participant to discuss his limitations. The lack of information sharing leads to misunderstandings between the provider and the participant both about the level of disability experienced and as a result, appropriate treatments. When talking about having a surgery that he believes will help with his

disability participant six expressed his frustration at not being scheduled for the operation: *“They say that I’m too young and yet other people who are even younger than me have it done” (P6).*

Despite the many reports of frustration, there were also stories of understanding from health providers:

But it was a lady doctor and within 20 minutes of being there she brought up the subject of what it was like not being the breadwinner and everything and I was really quite taken aback. It was like someone had went bang, and hit the nail on the head (P11).

Physical and psychological dependence - Having to ask for help is the hardest thing.

Not being able to complete tasks to the same level as prior to injury or illness and being reliant on others is also another source of frustration for participants:

It’s hard, not being able to do the things that you used to do and having to ask people for help to do stuff... Most of the things I have to do, I need to get somebody else to do it. That was the thing I found hardest to accept at the start. It was the hardest (P4).

Participants discuss the frustration they experience when their own pre-injury/illness values and behaviours are not mirrored by others. Acceptance of other people’s priorities and level of ability is often difficult for participants as participant four explains: *“I get a bit frustrated waiting for people to do something and then they don’t quite do it in a way that you want to do it yourself” (P4).*

In some cases urgent need for and the lack of immediate assistance resulted in participants doing tasks independently, although not always in the safest of manners. The fear of further dependence also motivates the actions of some participants. Participant seven discusses this when he spoke about needing to go to the toilet when there was no available assistance:

...you sort of realise that you had to do it, either that or sit and pee in your pants, and there was no way I was going to wear a catheter. I saw some old men in that hospital and there was no way I was going to do that (P7).

Paradoxically, use of equipment which is perceived to mean increased dependence can actually result in greater independence as explained by participant ten:

I looked at a person in a manual chair and I looked at a person in a power wheelchair, I would say that person there, the power chair is more disabled...and going from the transition, going from a manual chair to a power chair is quite traumatic for an accepting part of it. But once you realise that independence that power wheelchair can get. I could only push on flat hard surfaces in my manual wheelchair, I can go anywhere [in a power chair] (P10).

Participants rely heavily on partners in all areas of daily life as participant eleven said: *“I mean I’d be stuck if we fell apart tomorrow. I’d be stuck. I mean I don’t even know our PIN numbers for our cards – nothing” (P11).* Dependence on telephones and medical equipment is also of concern to participants. Participants talked about not going into areas where there was no cell phone coverage and being conscious of having immediate access to a phone, medicines or medical equipment. As participant three explains:

...so it can be distressing because you know that if it continues on through you have the pump spray that you have to have with you all the time, you know if the pump spray doesn’t work you’ve got to go to hospital. You’ve got to ring 111 [emergency number] straight away to make sure that you’re safe. It’s a bit stressful on your life when you think that maybe you’d have to go to hospital (P3).

The ability to have control in their life is valued by participants. Participant eleven appreciates the way his doctor interacts with him regarding medications:

A lot of the doctors that put you on medication these days don't tell you enough about them to begin with. I've been pretty lucky like I said, the doctor that I have would give me the opportunity to look it up first (P11).

Some participants have adjusted how they think of assistance. Rather than being dependant on others they see their situation as taking on an organisational role in their own life, as participant ten says:

I'm independent you know. I need somebody to get me up but I arrange that so I've got it sorted you know... an able bodied person, even if they didn't want to get themselves up could get someone to get themselves up. I'm doing exactly that you know. I am independent... I still plan trips away and organise, I don't organise sport anymore like I used to. I organise my own life... (P10).

Acceptance and incorporating the need for assistance, whether it be from people, medicines or equipment, into daily life has been seen as a necessary part of living with a disability for most participants. As participants five and four say: *"It's more about doing what you can with the body that God or whoever has provided" (P5).* *"You get used to it and you realise it's just patience and you just move on and get over it" (P4).*

Relationships change - Some people just can't cope.

Relationships with participants' family and friends have altered as a result of the disabilities caused through injury/illness. Perceptions of others along with self-image impact on the lives of the participants.

Worrying about others - I should be able to do more.

Participants worry about the impact their disability has on loved ones, especially wives. Several participants had to relocate either to a disability friendly house in the same area or to a city closer to disability services and health providers. The extra work that is created and the inability to share in the work load as a result of the disability are of concern to participants:

[Wife] had the hardest part of the deal, because she ended up having to do everything to take care of everything. She had to arrange to shift from

Ranfurly down to here and trying to keep me out of the road from trying to poke my nose in, at the same time she was coming down every weekend to stay at the ISIS centre, she had two cars blow up on her and things turned to crap for her, then I would be on the tail end (P4).

The financial cost and need for constant care has also meant that partners/wives have given up work and leisure activities that they were previously engaged in. Participant eleven talks about sacrifices his wife has made due to his disability: “*She’d love to be a part of that but can’t, either because of cost or just being away and leaving me alone*” (P11).

The dynamics between partners have also changed:

normally we get home from work the both of us, and we’ve got something to talk about from what’s happened during the day and I’m always asking my partner how her day went and how things happen and what have you, but it runs out pretty quickly because I’ve got nothing to say for my day (P9).

Changes in the bedroom.

The sexual nature of relationships has also changed. In some cases this is due to the illness or injury and in others, the side effects of medications have impacted on sex lives. There are various ways in which sexual intimacy is affected, for example participants discussed: lowered or increased sex drive, the ability to have and maintain an erection, the sensation associated with intercourse, and fatigue, frustration and irritation that participants’ and their partners sometimes experience. Although the ability to engage in intercourse is important to participants, it is more important to satisfy their partner than achieve sexual release themselves. Participant twelve shared the importance of this saying: “*I would hate to lose [wife] if it was for a sexual reason*” (P12). Different methods are employed by participants when addressing sexual intimacy. Planning for sexual encounters and employing other forms of sexual activity adds to the sexual satisfaction and intimacy of the relationship. Participant ten shares: “*I am now a more what do you call it? Aware lover than I was pre accident... you can’t do certain things but you can make up for it in other ways*” (P10).

Changes in the parent - child relationship.

The psychological impact on family members such as children also worries participants. When discussing his young son, participant eleven remembers: *“there was this one time he had to phone to get my wife who was away at a friend’s, because I was being that – I was starting to choke, so it was quite traumatic for him” (P11).*

A lack of understanding of the participant’s limitations and condition especially from children created significant stress for some participants. Participant two reminisced about how overwhelmed he felt on occasion:

...we’ve got the washing baskets overflowing, we’ve got tea to do and the house needs work done around it. I’m physically not up to it and I could not cope with the barrage from two of the four of them [children] – What’s for tea? (P2).

Participants with children also worried about their limitations as a role model. There was a concern amongst some participants who had sons that their boys would grow up not knowing that what a man should be doing is going out to work:

My son hasn’t grown up as a teenager and seeing me work and be a breadwinner so to speak, so he doesn’t have a good picture necessarily of me as a father doing that role and that’s something that worries me. I feel he has a different level of respect for me that what he would have if he had grown up seeing me you know, doing the nine to five or whatever” (P11).

Conversely, another participant felt the way he coped with his disability provided a positive role model for his children, in not taking life and physical ability for granted: *“The good thing is the kids have seen how I’ve coped and what I’ve gone through” (P4).*

Most people don’t know how to deal with it.

Many participants reported that family and friends did not know how to interact with the participant after their illness or injury. A common method of dealing with the uncertainty was to avoid the participant. Participant four talked about how his family reacted to his disability: *“After I got crook I had my older brother that I never see. Never saw or had anything to do with us. Brothers and sisters were pretty much a non-*

entity” (P4). Some participants showed some understanding regarding the reactions that friends and family had. Participant four talked about the reasons his son stayed away saying: *“He just didn’t see dad as being the same dad. He didn’t like seeing me the way I was”* (P4). While participant one understood that *“Most people don’t know how to deal with it”* (P1).

While there have been difficulties in some relationships as a result of illness/injury, participants also reported many positive responses from friends and family members. Participant five talked about the help he had received from his family and his sister moving in with him in order to help: *“I’ve been very lucky in that way. They’ve just bent over backward to help with everything”* (P5).

People with disabilities should be invisible.

Self-perceptions along with the perceptions of others have an impact on participants. Comments which are possibly designed to be supportive can come across as patronising. Participant ten says: *“you know if there’s a couple of us in wheelchairs sitting at the bar – it’s good to see us out isn’t it? People say to us it’s good to see you out”* (P10). The over emphasis placed on how good it is to see people with disabilities out socialising gives an impression that people with disabilities should not participate in public life and are *“meant to be locked away in a room... they’re not meant to have lives”* (P10). A common perception is that intellectual disabilities or ability to hear and communicate go hand in hand with physical disabilities. Participant four talks about the frustration he and his wife often experience:

...because we used to get people coming up to us and they would talk to [wife] and say “aww how is [participant] doing now? “Mmmm I’m down here” and she’d get frustrated and say “well he’s sitting there, he’s not deaf, just ask him” and that was the biggest thing, people’s perception of what you were once you were in a wheel chair they just look over you, they’ll treat you as in the third person (P4).

My life is not my disability - I am still a person.

Constant discussion about the participant’s injury/ illness is also a cause for annoyance. When attending social events participant eleven explains: *“I got people I knew coming up to me and asking me questions and it got to the point where I wouldn’t go*

anymore...because I didn't want to answer difficult questions, I just stopped going" (P11). Another common perception voiced by participants is that people with disabilities are asexual. As one participant says:

I have a bit of a joke with my partner, you know, we'll be introduced to someone and someone will think that she's my nurse. Because people do think that you know – you can't, have a partner you know. You're disabled, you're useless. And I'm always telling a joke that you know I'm no threat to your wife or you know. Little do they know I could be the worst kind of threat. Because you know I have had a couple of affairs with caregivers who were married... (P10).

Participants voiced, also sharing some of these perceptions in the early years after their injury/illness. Participants reported feeling that women would not be sexually attracted to them because of their disability: *"nobody loved me and I was never going to have a girlfriend"* (P7).

Unsolicited physical assistance can also be seen as condescending as participant six explains:

I don't believe that I do struggle with it, but they see me and they'll say "no we'll get that, we'll get that" and I'm thinking hang on I'm part of a team here and they say "no we'll get it" so I take a step back and they grab it and think well alright. So yeah it's not a good feeling, but there's not a great deal I can do about it (P6).

Participants also talked about a lack of understanding from others about physical restrictions their disability had on their lives. There was a perceived need from participants with non-visual disabilities to have suitable justification for their lack of participation. Participant twelve explains:

I think you've got a fear of it and you want to tell people, "look I'm not that well" you want to tell them "I'm not as strong as I seem" [in case others think] you sort of want a sympathy vote... you're trying to make excuses for yourself you know, for why you can't do that work anymore (P12).

The physical environment also has an impact on participants' ability to be involved in social situations. Participant twelve talked about the weather affecting his ability to leave the house:

I was cold. I got very cold, what May, June, July, August, that is a cold time of year. I couldn't move away from the fire, I was virtually in the fire. I had to sit in the seat right here with the fire going with my feet up to keep warm (P12).

Participant two talked about other environmental issues he faces when leaving the house:

They've got the lights dimmed and the candles there, but they don't realise candles in 95% of cases are made from paraffin wax. Paraffin wax is a chemical, petroleum chemical... and it causes me problems...I said the perfume, the deodorants, the fact that you smoke, your hairspray or your house is full of fragrance – I cannot visit you at your house or I cannot go out with you because my lungs and my brain cannot cope...(P2).

The difficulties faced by participants contributed to a lack of enjoyment in activities they used to participate in as explained by participant ten:

Like going on a bus trip, a bus trip with the guys – I had to sit at the front of the bus because I had to get lifted into the bus and I would normally have been up the back of the bus playing cards and you know, so that just wasn't my thing (P10).

Having people come to visit also brings its own set of issues. Limitations not only affect the participant but also their families as participant eleven explains:

It affected me socially as well as my wife and son. I also got reluctant for people to just call in whenever they liked because quite often I would be in a bad way... you know you don't want to have to entertain people when you're like that you know... I think a lot of people don't understand you can't plan when you're not going to be well (P11).

Some people took the additional requests around visits as strange and have reduced contact with participants as a result. Avoidance of situations was a common method of dealing with explanations for non-involvement. Excuses such as work or prior engagements are used. Not being able to be involved in social situations has an impact on the participant's own feelings of self-worth: *"It's demoralising" (P6)* and *"You feel very much alienated from other people when you don't see them" (P12)*.

Loss and change.

Loss has been a significant theme throughout the interviews. I have talked about how participants have experienced loss of paid employment, physical ability, leisure activities and relationships however loss has not stopped there. Memory, recall, speech, ability to drive, read and write and physical appearance have also been affected. As participant ten says:

So the chair is more than just losing your mobility, it's your bowels and your bladder don't function properly, your muscles can spasm. There's a whole raft of problems and little procedures you've got to go through... I didn't know anything about all the other side effects, the bowels, bladder, pressure areas... and all of a sudden your tummy muscles just drop, and you get this pot on your tummy. It's not about, nothing to do with you eating lots or drinking lots, it's just your tummy muscles are not there anymore, don't work, so everything drops. That's the most devastating part for me (P10).

Loss has resulted in periods of depression and in some cases, suicidal thoughts. As participant seven explains he felt *"[life] wasn't worth living. I'm now a cripple" (P7)*. Participant two talked about not only losing his job, but also a place of solace, a place he could go and not think about his health and the changes he was experiencing in his life: *"I'd just burst into tears and think to myself – well what have I come down to? You know? Where are my kids? I've lost my house. My wife doesn't want me" (P2)*.

In most cases participants have worked through many of their negative feelings regarding their disability and despite the stories of loss, there are also positive stories relating to disability. Most of the participants report if given the opportunity, they would not change having their illness/ injury. Participants spoke about being exposed to

new opportunities and people that they would not have met had they not experienced their illness/ injury. Participant four explains:

I've never regretted what's happened because I've met people and done things that I never would have, I never would have met before so I've never classed it as a bad thing it's just sort of put me down a different pathway... it's probably made me smarter in some aspects. I've learnt a lot about myself and how things work as far as the body goes that I wouldn't have thought of before and doing things. If I want something done I'll work out a way to do it (P4).

Focus on what a participant can do, rather than what they cannot do increases confidence as participant two says: “*So you feel robbed of your competency and your confidence. It takes a hell of a dive. But then you start to ask yourself what can I do? Where can I be some good*” (P2). Participant seven reiterated these thoughts when he spoke about community “*organisations [which] helped because they accepted me for what I could do and not what I couldn't do*” (P7).

The competitive nature of some of the participants has contributed to a positive view of their disability. Competing and being better than others has led to an increased self-esteem in participants. When talking about his time in the spinal unit at the hospital participant ten said:

[there was] quite a lot of goals to achieve and I liked achieving goals and even though I was lying flat on my back... I still relished in the environment of trying to do better than the guy on the next bed (P10).

Participant twelve reiterated this sentiment saying: “*You generally try to find comparability with someone. It's even competitive to some extent like a pacemaker and I say well I've got a defibrillator, mine's 50 grand's worth compared to your ten*” (P12). Participant one spoke about how good he felt competing against able bodied people: “*When you can lift more [weights] than most people in the gym, most able bodied people, makes you feel pretty awesome*” (P1).

Being conscious of others in situations worse than their own is another method participants utilised in viewing their disability in a positive light, as participant nine said:

You think about these people that are a lot worse off and that makes you think shit, you know, you're not so bad, you know. You get into a bit of an upset and you think about things because you're not doing anything with your mind, you know you're not working. You're not in a different situation. That would stop you thinking about things like that, you know. Yeah there's a lot worse off out there (P9).

Masculinity and Summary

When participants thought back to their pre injury/ illness life and what they considered it meant to be masculine and what traits a man would have, participants had very clear ideas that a man was a good provider, husband and friend, a good role model for children, reliable, independent, physical and played sports, drank alcohol and socialised often. The disabilities experienced by the participants have had an effect on many if not all of these areas.

As a result of their disabilities, participants have experienced great loss in their lives. This has had a great impact not only on the participants but also their friends and family. However in most cases participants have been able to reconcile some of their masculine ideals with their current physical capacity and embrace the changes in their lives. In some cases men have changed their opinions on the importance of masculine ideals as participant five says:

Masculinity isn't a big issue to me anymore. It used to be when I was young, but I think it was because of marketing and things like that. So the fact that I do the dishes every morning doesn't make me feminine or anything like that. It suits because I am a morning person (P5).

A changing social climate was discussed by one participant as a contributing factor to this. He felt that because women were taking on roles in the workplace that were traditionally filled by men, that gender lines have become blurred and it has become somewhat acceptable for men to take on some domestic roles. Other participants talked about the natural aging process and that although their disability had prematurely limited their abilities, now that they were older, some of the limitations were age appropriate.

Substitution is also a common method employed by participants. This is clear when talking about how participants occupy their time. Daily activities were commonly talked about in terms of work. In cases where participants are no longer able to continue in paid employment they have found other areas of meaning where they can contribute and still see themselves as working in these roles.

Typically masculine traits which are not traditionally seen as positive, such as being competitive, stubborn, determined and angry have in some cases been channelled into achieving goals. As participant one says of all the pent up frustration he experiences due to his disability “*anger is a gift*” (P1). Without his anger he would not have the motivation and determination he has to put into his recovery.

Regardless of the age that participants experienced their illness/ injury, the themes remained the same. Participants in most cases have adjusted their lives and masculine identity to fit their current situation. However societal opinions still have an impact as Participant ten says: “*But I know other people would look at you and think – you’re only half a man now you’re in a wheelchair, where’s the other half?*” (P10).

In this chapter I have described the findings which arose from the research. In the next chapter I will situate these findings in the context of the existing literature base regarding injury and illness and its impact on masculinity.

Chapter 5 - Discussion

In conducting this qualitative descriptive study, I have sought to answer the question: What effects do acquired illness and injury and subsequent changes in occupational roles have on men's self-perceptions of masculinity? In answering this question I first sought to understand how men view their own masculinity before and after an acquired illness or injury. Through the research process I then explored how disability challenged men's perceptions of masculinity.

The purpose of this study was to address some gaps in the literature surrounding the interaction of illness and injury on perceptions of masculinity and to contribute to the body of knowledge on this topic. Men involved in this study defined themselves as men or masculine in various ways. There were clear differences between before injury/illness and after injury/illness in the way these men both enacted their masculinity and how they thought of themselves as men. From the findings of the study there came many parallels to the existing literature; however in addition to these similarities, there were also areas that did not feature strongly in the current writings and in some cases were only found in a small section of one article.

In this chapter I will discuss the findings in relation to the current body of knowledge under the themes of: work, depending on others and establishing control, sex and sexuality, sports and socialisation, and masculinity and occupation. I will then discuss the strengths and limitations of the study and suggest areas where further research may be beneficial.

Findings

Work: The measure of a man.

Prior to experiencing illness or injury the men involved in my study were all engaged in full time employment or in the case of the two men who were of school age, in full time education - one carried out additional part-time employment at the time of illness/injury. Work in the form of paid employment was central to both the participants' lives and their self-esteem. For the men with families, the ability to provide financially and role model hard working behaviours to their children was also paramount to their identity as men. The emphasis participants placed on work as central to their lives and identity is reflected in the literature.

One of the main assumptions of both traditional and hegemonic masculine frameworks is that men should be the economic providers for the family (Beigi & Cheng, 2010; Jones & Curtin, 2010; Kilkey & Clarke, 2010; Parse, 2001; Sparkes & Smith, 2002; Wada et al., 2010). Fathering was also often seen in terms of financial provision, both in terms of my study findings and within the literature (Jones & Curtin, 2010; Kilkey & Clarke, 2010; Mfecane, 2012; Siu et al., 2013; Wyrod, 2011). This view of fathering is reproduced within literature specific to New Zealand (Callister & Fursman, 2013). Participants voiced the importance of role modelling being a worker, in paid employment, to their children. Concern was voiced by some participants that the loss of their own worker role would mean they were not able to fulfil their fathering duties. This was because it was perceived, by some participants, that part of being a father was being a role model for what it really meant to be a man, which was to be a worker. Having money to buy items for children and do activities was considered important to participants. In many cases income was limited and participants were not able to provide to the same level as they did prior to illness or injury. Even for those men who are not married or otherwise in a relationship where there is a financial responsibility for another person or people, work is still considered one method to establish the measure of a man. This assumption is not solely confined to the western world, the fears associated with loss of employment, and consequently masculine status, transcends cultural barriers (see for example Mfecane, 2012; Siu et al., 2013; Wyrod, 2011).

Men are often defined by the work that they do and work is commonly central to a man's sense of identity and well-being (Jones & Curtin, 2010; Stone, 2003; Wilcock, 2003). That is, when the ability to work is removed then so is the ability to identify and define oneself as a worker and therefore as a man. Stone (2003) found in her qualitative study of 54 injured workers that "being injured at work means that not only is their livelihood threatened but also their place in the world" (p. 7). Although Stone's study looked at both male and female workers, many of the quotes used throughout her article were from men and the overarching themes were congruent with both my study findings and the current literature base regarding injured men.

Regardless of financial income, the ability to work and to be seen as a contributing member of society was important to study participants. Participants re-created their identity as workers in various forms. Voluntary work was one such method and was often seen as 'giving back' to society. This type of work typically

consisted of speaking to people such as university students and others experiencing similar illnesses or injuries, and being involved in management and committees of various groups and organisations. Other participants renegotiated and reframed their daily activities as work. Daily occupations were discussed in the context of management rather than receiving assistance and activities previously considered to be leisure became central to managing the participants' health, well-being and lives.

The ability to renegotiate a worker identity had an impact on how the participants viewed their own value. For the men who were financially dependent on their partners, and where there was not an established worker identity there was a strong feeling of being a burden. Feelings of uselessness were disclosed along with thoughts of leaving a marriage in order to become less of a burden to wives or other family members. No longer being able to financially provide for loved ones weighed heavily on the minds of those participants who were reliant on partners for financial support. Although the participants in this situation discussed the contributing to the family in a more practical manner such as completing household tasks, their physical abilities meant this was not always possible resulting in an even lower sense of self-worth and esteem.

Alternatively, participants often reported an increase of self-esteem when experiencing external validation. Positive feedback, concessions and effort made by others to incorporate or work around a participants' health status and abilities contributed greatly to participants' sense of self-worth. These findings are echoed in the existing literature. Coles (2008) found in his study discussing the life experiences of 41 men from a variety of backgrounds that men who were able to renegotiate their masculinity were more secure in themselves and their identity as men and did not feel marginalised or subordinated by society. Kerr and Ballinger (2010) had similar findings in that a sense of identity and life satisfaction was intertwined with the ability to renegotiate, adapt and find meaning in daily occupations such as work and leisure activities.

Depending on others and establishing control.

As discussed in the previous section, being financially dependent on a partner can contribute to feelings of uselessness and lowered self-esteem. Participants who had an external source of income regardless of the level of this income spent little to no time focusing on how financial dependence impacted on their personal relationships, rather

they discussed financial dependence in terms of interaction with agencies such as ACC or WINZ. Reliance on government agencies was a source of embarrassment and participants felt the processes involved in obtaining such income were degrading and humiliating. Dealing with agencies that had the authority to grant or decline financial assistance commonly left participants feeling vulnerable and powerless to request additional assistance for which they were often eligible. Participants reported confusion at systems perceived as foreign and the constant questioning of medical reports by case managers and other agency staff who often had little to no medical expertise or training. The continual questioning of participants' ability and medical status gave the impression of non-belief to some participants who felt they were constantly being watched, judged and considered to be untruthful or fraudsters. Interactions with these agencies sometimes became a full-time job in itself. These interactions often served to reinforce the 'sick' role and already established feelings of worthlessness in some participants.

The existing body of literature has, in many cases, a focus on the loss of the 'worker' role and how this might impact on perceptions of masculinity however there is only passing comment regarding the effect that reliance on state and social agencies might have on men's own perceptions of masculinity (Beigi & Cheng, 2010; Cecil et al., 2010; Jones & Curtin, 2010; Kilkey & Clarke, 2010; Schopp et al., 2007; Sparkes & Smith, 2002; Stone, 2003). Interactions with ACC and WINZ were a significant theme within my research. This may be, in part, due to the nature of the compensation and social support systems in New Zealand in comparison to what financial support may be available in other countries where this topic has been explored.

Another aspect of my research that came through as a strong theme in my research, but was only addressed in one small section of one article in the reviewed literature (Olliffe & Phillips, 2008), was the expectation of participants in regards to the knowledge of health professionals. There was often assumption on behalf of participants that all health professionals had specific knowledge on the nature of the injury or illness and that specialist doctors in particular would be able to 'fix' the problem. The participants often believed that health professionals should know about the functional limitations participants experienced, based solely on diagnosis and test results and without any verbal input from the participant himself. In part this may be due to the age of participants who had primarily been raised within a society reliant on a medical system which was heavily influenced by the biomedical model of health

(Fougere, 1994; Sheridan et al., 2011). The frustration and questioning of a doctors ability following consultations was another contributor to feelings of powerlessness experienced by participants.

Oliffe and Phillips (2008) link the frustrations reported by participants when dealing with health organisations and practitioners to men's lack of help seeking behaviours. These authors found men might be less willing to access health care services due to previous negative experiences. There are many theories as to why men do not engage in help seeking behaviours from the hegemonic beliefs and social pressures that men should be tough and 'harden up' to the style of waiting rooms and the attitudes of health professionals (O'Brien et al., 2005; Oliffe & Phillips, 2008; Stibbe, 2004). However, with the exception of Oliffe and Phillips (2008) there is little focus on the role men's own beliefs regarding doctors abilities and knowledge, and the amount of information they themselves have to impart, might have on men's help seeking practices.

In addition to financial and organisational dependence, participants spoke about the physical and emotional dependence they experienced. Having to rely on others for a myriad of tasks from getting out of bed, showering, toileting, eating and other personal tasks to completing odd jobs around the house was a source of great frustration to participants. However in addition to the frustration physical and psychological dependence created, participants also voiced concerns about the additional psychological, emotional and physical strain placed on loved ones, such as wives, partners and children, who were providing this support. Not being able to help with house hold tasks, requiring physical assistance, and the restrictions placed on loved ones in their own lives featured both in my own study as well as within the reviewed literature (Emslie et al., 2006; Gibson et al., 2007; Gray et al., 2002; Kilkey & Clarke, 2010; O'Brien et al., 2005; Oliffe et al., 2010; Ostrander, 2008; Tepper, 1999).

It is clear that dependence is a significant issue for men living with chronic disability arising from illness and injury; therefore it is not surprising to then also see that the ability to take control where ever possible is very important to men living with illness or injury. Reformulating the concept of dependence into one of choice, organisation and control was discussed by participants. Having the ability to direct and organise people in tasks, and make choices regarding how and when assistance was given along with being given information and choices about whether or not to try new

medications was discussed by participants as gaining control in their lives. Some form of control, no matter how little this appeared to be, was valued by participants.

Sex and sexuality.

Sex, sexuality, and sexual function are all aspects of men's lives that were discussed by participants. Although this is a significant aspect of most men's lives, it was interesting to note that participants who had a support person present were less inclined to discuss this area of their lives. Participants who initiated discussion of a sexual nature discussed sex, sexuality and sexual function under differing guises. Participants discussed the common societal impression that participants were not able to be sexually active either due to their physical disability or that their illness or injury would render them unattractive to the opposite sex. In addition, participants discussed the changing nature of sexual relations post injury or illness.

Men with disabilities are often considered to be asexual. It was sometimes considered to be an inside joke to some participants, that people often make (usually incorrect) assumptions regarding the participants' sexual function. This experience is reflected within the literature on sexuality and disability (Burns et al., 2009; Lindemann, 2010; Rapala & Manderson, 2005; Shakespeare, 1999; Tepper, 1999). In his qualitative research of 21 men living with a variety of disabilities, Shakespeare (1999) also discussed the notion that men living with disabilities are considered to be asexual and 'safe'. The idea that men living with disabilities are 'safe' and not a sexual threat was voiced by several participants. Some participants reported that husbands and male partners of non-related women, who were in the social circle of participants, expressed a lack of concern regarding the fidelity of their female partners whilst in the company of the participant. In several instances, this pre-conceived notion of asexuality resulted in the women's ability to conduct extra-marital affairs with a participant with absolutely no suspicion on behalf of her husband or partner.

Along with societal opinions regarding sexual ability, a belief was voiced that the effects of illness or injury rendered the participant sexually unattractive. This belief had reaching effects, with new partners often being questioned about what they saw in the participant they were dating and concern for the 'burden' they might be taking on. In his auto-ethnography and incorporated literature, Tepper (1999) shared his own similar experience regarding the concern both his and his future wife's families voiced regarding the 'burden' his disability would be on his wife. The pervasive belief that

living with a disability equates to being sexually unattractive was also espoused by some participants when talking about the earlier years following their injury or illness. Although these ideas dissipated somewhat over the years following the primary illness or injury, the initial belief that they did not have anything to offer a partner and would never have sexual relationship impacted greatly on participants who were not married or in a long term relationship at the time.

For participants who were married or in a long term relationship at the time of injury or illness, the change in sexual relationships was discussed. Some participants talked about the changes in relationship dynamics affecting their sex lives. For example, fatigue played a significant role in initiating intercourse. Disability sometimes meant that both partners for varying reason were too tired to engage in sexual activity. Function and decreased sensation was a concern for some participants; however the majority of participants discussed their sex lives in terms of substitution. It was pointed out that although there may be some limited capacity for certain sexual actions, there was more than one way to achieve sexual satisfaction and some creativity was often engaged. In addition, priority was often given to intimacy rather than penetrative sex and the focus on sexual satisfaction was commonly shifted to the partner rather than the participant. The renegotiation of beliefs regarding sex and sexual ability is comparable with the reviewed literature (Burns et al., 2009; Gray et al., 2002; Ostrander, 2008; Shakespeare, 1999; Tepper, 1999). However the decline in sexual needs being aligned with the natural aging process (Gray et al., 2002) did not feature in my study. This may be due to the age and type of injury or illness that participants experienced.

Loss, change and renegotiation

Throughout the many stories participants told, were tales of loss. Loss featured heavily in all areas of participants' lives. Stories were shared about losses in areas of variety of physical, cognitive, emotional, social, family, and roles. Participants talked about the obvious losses such as movement and ability to walk, however it was often the less obvious losses in their lives which sometimes had biggest impact on participants' sense of self, for example, muscle atrophy in the abdomen area. Loss in some cases lead to further problems such as low self-esteem, depression and suicidal ideation. These findings are consistent with the literature (Good et al., 2006; Molyneaux-Smith et al., 2003; Ostrander, 2008; Schopp et al., 2007; Tepper, 1999).

How participants coped with these losses made significant difference to the outcome of how satisfied they were with their lives. Some of the participants, who had not come to terms with their illness or injury, reported experiencing various negative emotions. There was not a time limit on how long it took for participants to accept their health situations. In the case of one participant, who reported still feeling extreme anger and frustration regarding his health, it has been decades since his initial injury/illness.

Along with loss there were stories of acceptance. Many participants talked about the positive aspects of their illness or injury. For example, although there were social losses in the form friends and family, injury or illness was reported as key to facilitating a more full life for example by meeting new people who the participant would not have typically socialised with prior to illness or injury, being exposed to new experiences. Some participants reported much personal growth due to their illness or injury and that the positive aspects of their illness or injury far outweighed the negative. These participants reported that they would not change anything about their lives if given the chance, which included their illness or injury.

The ability to accept a new health situation appeared to be linked to the ways in which participants were able to incorporate their health situation into existing personal schema. Stories of renegotiation were commonplace amongst the men who reported that they would not change anything about their current health situation. It seems the ability to renegotiate existing belief systems is central to achieving positive outcomes for men living with the long term effects of illness or injury.

Sports and socialisation

Sports, in particular rugby union, were considered an important part of participants' lives prior to injury or illness and provided a space for socialisation. Rugby union has long been associated with men and masculinity in New Zealand (Du Plessis, 1994; Park, 2000; J. Phillips, 1987). Given this association it was not a surprise to hear stories regarding the competition, camaraderie and mateship that were associated with the sport prior to injury or illness. Additionally, given that participation in sports was also a significant theme within the reviewed literature (Gaskin et al., 2010; Gibson et al., 2007; Lindemann & Cherney, 2008; O'Brien et al., 2005; Park, 2000; Rapala & Manderson, 2005; Sparkes & Smith, 2002; Taub et al., 1999), I had some expectation that sport would also be a central theme within my own findings. However, although

this theme was touched on within my own findings, there was not much emphasis placed on participation post injury or illness as was found in the literature.

Participants instead spoke about the changes in fathering roles and friendships, and difficulties associated with maintaining previous social relationships and renegotiating social spaces. Some participants with children talked about their inability to engage in the assumed fathering activities of throwing a ball around or taking children out to play sports. The inability to connect with their children through physical activity was of concern to some participants. Other participants spoke about changing the types of activities, they engaged in with their children such as substituting rambunctious activities with more sedate interests such as reading or model making.

Social and environmental barriers played a significant role in participants' social lives. People's attitudes and understanding, or lack of, often impacted on how comfortable the participant felt in social settings and in many cases the participant self-isolated due to negative experiences. For some participants, fear of the unknown and increased feelings of vulnerability also contributed to this self-imposed exile of social activities. In addition to the attitudinal barriers, environmental barriers also meant that participants did not engage socially in the same manner as they had prior to injury or illness.

Some participants spoke of the loneliness and alienation that they felt due to their illness or injury while others spoke of substituting types of social settings and the activities engaged in, for example drinking alcohol. Competition, which was a key factor in sports participation, was also renegotiated. Instead of competition on the rugby field, participants spoke of new forms of competition such as who had the fanciest pacemaker or wheelchair. Discussion regarding who was worse off health-wise and who had made the most physical gains, featured alongside stories of engaging in activities where the ability to perform on a higher level than able bodied people was a source of pride and competition for participants.

Reformulating aspects of masculinity, for example, by positioning rehabilitation as a challenge to be overcome, or help seeking as bravery and experiences of these, provides men with a platform for "compelling tales of men's resilience" (Olliffe et al., 2010, p. 5) and allows men to embrace rehabilitation and health promoting activities while still conforming to masculine norms. By "selectively supporting adaptive aspects of traditional masculine roles" (Schopp et al., 2006, p. 1161) therapists are able to facilitate positive outcomes for their clients. The success of incorporating masculine

practices into therapeutic practice is documented in the area of depression. Oliffe et al. (2010) found, “approaches to depression and suicide prevention that specifically address masculine practices will offer more success than those that are gender neutral” (p. 7).

However, it is important for therapists to also consider aspects such as timing of such interventions as starting them “too soon in the recovery process could be detrimental to both the effectiveness of the treatment and the individuals overall adjustment” (Schopp et al., 2006, p. 1161). Jones and Curtin (2010) concur with this and also warn,

If rehabilitation professionals focus only on the performance of occupation and do not address the process of identity transition as a part of rehabilitation, such men may continue to have difficulty adjusting to and accepting their new roles and finding value and meaning in the things they are able to do. (pp. 10-11)

Masculinity and occupation

Gender as something that we ‘do’ is not a new concept (Beagan & Saunders, 2005; Connell, 2005; Du Plessis, 1994). In the seminal work titled *Masculinities*, Connell (2005) defines gender as “as a social practice that constantly refers to bodies and what bodies do” (p. 71). People ‘do’ gender. It therefore follows that when the body is unable to perform to an appropriate capacity, such as when due to illness or injury; gender itself is challenged (Connell, 2005; Lindemann & Cherney, 2008). Occupation is also described as what people ‘do’ (MacKinnon & Miller, 2003). The differences within gender roles and occupations which are attached to them are discussed within various literature (Primeau, 2000; Wada et al., 2010). Discussions on how masculinity is challenged, and what men ‘do’ in order to re-establish their masculine identity when working in typically female dominated professions is also found within literature (Henson & Rogers, 2001; Lupton, 2000; Simpson, 2004). However, masculinity as an occupation has only been discussed in one article that was able to be sourced (Beagan & Saunders, 2005). Throughout this study, it became obvious to me that participants were both consciously and subconsciously concerned with, and indeed occupied with, doing masculinity and recreating their own masculine identity.

Stories regarding the renegotiation of occupations and behavioural ideals typically associated with masculinity such as the worker role and competitiveness were

commonplace amongst many participants. However, implicit within these stories were also stories of recreating masculine identity. My findings support those of Beagan and Saunders (2005) that masculinity, as well as contributing to occupation, is also an occupation in its own right. It appeared that participants with more stories of how masculine ideals and identity were adjusted and incorporated into their current health situation, also enjoyed a more positive personal outlook. Indeed, many of these men reported that they had a more full life now than prior to their injury or illness, and that they would not change a thing given the opportunity.

Strengths and Limitations

This study was valuable in discussing some of the gaps in the literature regarding men in New Zealand and the impact acquired injury or illness and subsequent changes in occupational roles might have on self-perceptions of masculinity. There were various strengths and limitations to this study, some of which are discussed here.

Robertson (2006) discussed the importance of recognising the role a researcher's gender might play in men's health studies. Although Robertson's article was discussing the need for increased reflexivity amongst male researchers in the area of men's health, it is nonetheless important for me to recognise my gender as both a strength and possible limitation to this study. It could be argued that men might have a greater rapport with men and therefore being a female researcher in the area of masculinity would be a limitation. However, health is traditionally considered to be the domain of women and men who venture into research in this area are often required to first establish their own masculinity with study participants (Oliffe, 2010; Robertson, 2006). Perceived power relations to do with gender and class may impact on the type of information gained (Oliffe, 2010). From the existing literature base on masculinity and health it would appear that men might be more open to discussing their health with a woman given the masculine ideals of appearing strong and disinterested in one's own health and possible masculine posturing around other men (Gray et al., 2002; Oliffe, 2010; Robertson, 2006). However, in saying that, it is possible participants might have disclosed different information to a male interviewer or a male disabled interviewer.

My own background as a woman living with disability could also be considered both a strength and limitation in this study. My own experience within the health system meant I had a greater sensitivity to some of the issues faced by study

participants. Indeed, I found a small amount of self-disclosure and empathy prompted participants to discuss their experiences in more depth. My study was conducted under a constructivist paradigm, relativist ontology, and subjective and transactional epistemology, as such it was recognised that as the researcher, I was active participant in the research process (Denzin & Lincoln, 2011; Guba, 1981; Lincoln et al., 2011). As an active participant in the research I cannot always know to what degree I am affecting the information given. However, every effort was made to minimise this effect through the comprehensive reflexivity and robust measures put in place to address trustworthiness (Bloomberg & Volpe, 2012), as discussed in Chapter Three.

This study was not designed to be an all-encompassing answer to the ways in which every man might experience changes in masculinity due to illness or injury. Nor are the findings assumed to pertain to every man living with an acquired illness or injury. Rather, it was a study looking at a select number of men, defined by the inclusion and exclusion criteria, and their own personal stories. These stories gave an invaluable insight into the lives of these men and how their acquired illness or injury and subsequent changes in occupational roles impacted on their perceptions of masculinity. Although the study was not limited to heterosexual men, all study participants identified as heterosexual. In addition all respondents were above the age of 39. Some additional purposeful sampling to include both gay and younger men may have been beneficial.

There are a number of additional factors that might be considered limitations within this study. The small sample number of twelve participants could be considered a limiting factor within this study. However, as data saturation (also known as thematic saturation or informational redundancy) had been reached, this number of participants was considered to be satisfactory for this study (Lincoln & Guba, 1985; Sandelowski, 1995b). Rather than looking at one cause of disability, participants involved in this study lived with a range of injuries and illnesses. Although more study participants might have provided some variety for comparison within each illness or injury experienced; it was established through the reviewed literature, that regardless of injury or illness, the stories being told were similar in nature and had common themes.

Areas for Further Research

The findings from this study suggest a number of areas where further research might be beneficial. The impact illness and injury has on masculinity is an area that deserves more extensive inquiry. Occupational therapists are uniquely positioned to conduct this type of research due to the particular focus on occupation. My findings clearly showed that participants were occupied in renegotiating and reproducing their masculinity after illness or injury. Masculinity as well as contributing to occupation is an occupation itself. Occupational therapists need to listen and be aware of the stories men tell around how they have restructured and renegotiated all occupational areas of their lives including masculinity. It is important not to assume deficit, particularly in the area of work, where participants have told stories of how they are engaged in activities they considered to be work. Terminology and rehabilitation input should be framed in terms appropriate to the masculine ideals of individual men. Research which resulted in a framework or guidelines for health practitioners working alongside men would be valuable to all health professionals.

Although my findings support the existing international literature base in the area of how health status might impact of self-perceptions of masculinity, there is only one other study I am aware of that discusses this topic within a New Zealand context. New Zealand has a unique ethnic and cultural composition. This study, conducted in Dunedin, New Zealand, had a limited range of ethnicities and sexual orientations. Only one participant identified as Māori, while another disclosed a Māori heritage, he did not identify as Māori. The remainder of participants identified as various combinations of New Zealand European or Pākehā. No men identified as gay, bisexual or transgendered. It would be valuable to repeat this study within other geographic locations, both rural and urban, and with a wider ethnic range of men with differing sexual orientations in order to provide comparison and contribute to the body of knowledge in this area.

This research was conducted with men who had been living with the effects of their particular illness or injury for a significant period of time. Given the findings around participants thoughts of masculinity prior to illness or injury were typically traditional in nature; it may also be beneficial to investigate men's perceptions of masculinity in acute rehabilitation settings as well as within a time frame closer to the initial injury or illness.

Conclusion

Hegemonic Masculinity informs every aspect of a man's life regardless of whether they conform to the standards or reject them. Although masculinity informs occupational roles, it is also an occupation in its own right. Illnesses and injuries can challenge masculine status and result in loss of identity, they can also change men's abilities in many areas, transforming their occupational roles and providing a challenge to their self-perception of masculinity.

The findings that have emerged from this study have shown that participants were occupied in recreating and renegotiating their masculinity. A focus on masculinity as an occupation is important as occupation can provide empowerment and meaning to a man's life, and can assist him in coping with life changes due to illness or injury.

There is a paucity of research regarding the impact health status has on masculine perceptions. Further research, conducted within a New Zealand context, will be invaluable in validating the current findings in this area. In addition, new studies which explore the narratives of men experiencing a wide range of illnesses and disabilities will also be beneficial to understanding how men view themselves within a masculine framework. The application of this knowledge is an area requiring extensive exploration and research. There is significant scope for healthcare professionals to gain understanding of men's relationship to, and their self-perceptions of, masculinity and to utilise and incorporate these findings into therapeutic settings, therefore gaining more valuable outcomes for their clients.

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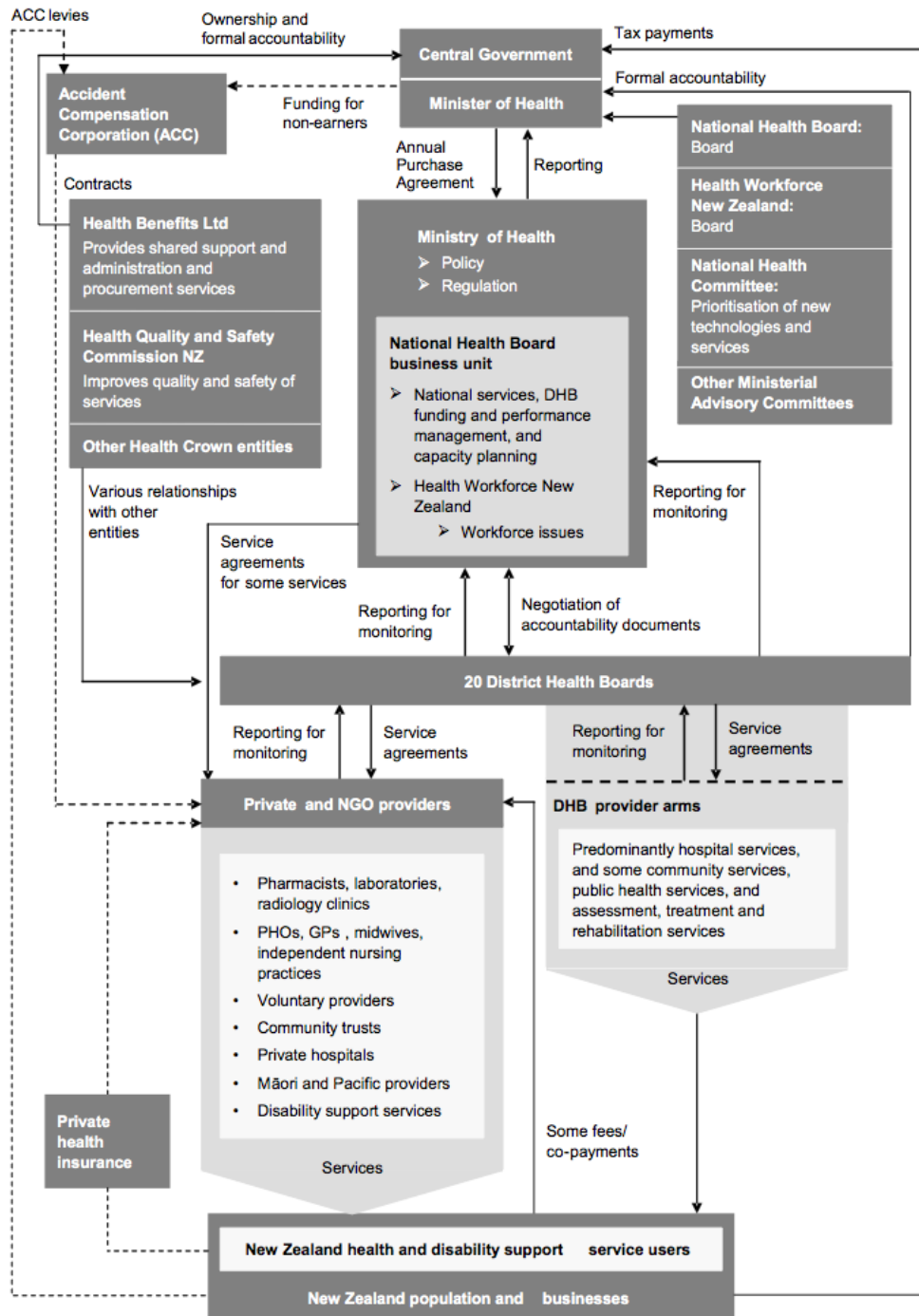
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Appendix A

Structure of the New Zealand Health and Disability System



Note. From “The New Zealand Health and Disability System: Organisations and Responsibilities: Briefing to the Minister of Health” by Ministry of Health, p. 2. Copyright 2012 by Ministry of Health. Reprinted with permission.

Appendix B

Literature Included in Critical Review

<u>Reference</u>	<u>Country</u>	<u>Discipline</u>	<u>Design</u>	<u>Sample</u>	<u>Conclusions</u>
(Braveman & Helfrich, 2001)	U.S.A.	Occupational Therapy	Narrative Analysis	N=3 who completed vocational programme for people living with HIV/AIDS	Occupational Performance History Interview helps to understand how AIDS impacts occupational identity
(Brownhill, Wilhelm, Barclay, & Schmied, 2005)	Australia	Psychiatry	Grounded Theory	N=77 Men N=25 women for comparison	Gender differences in the expression of depression. Emotional distress can be constrained by traditional notions of masculinity
(Bullen, Edwards, Marke, & Matthews, 2010)	U.K.	Psychology	Interpretive Phenomenology	N=9	Men experience altered sense of masculinity post-surgery from penile cancer
(Burns, Hough, Boyd, & Hill, 2009)	U.S.A	Medicine	Internet Survey incorporating instruments to measure depression, environmental barriers, social support, sexual prowess and sexual desire	N=116 Spinal Cord Injury	Strong sexual desire results in higher levels of depression when endorsing masculine norms for sexual prowess
(Cecil, McCaughan, & Parahoo, 2010)	Northern Ireland	Nursing	Qualitative Pilot Study	N=8 with previous cancer diagnosis	Cancer support services need to be gender sensitive to ensure interventions do not undermine masculine values

<u>Reference</u>	<u>Country</u>	<u>Discipline</u>	<u>Design</u>	<u>Sample</u>	<u>Conclusions</u>
(Emslie, Ridge, Ziebland, & Hunt, 2006)	U.K.	Social and Public Health	Qualitative secondary analysis	N=16	Masculine traits had positive and negative impact on depression and suicidal ideations
(Gannon, Guerro-Blanco, Patel, & Abel, 2010)	England	Psychology	Foucauldian Discourse Analysis	N=7	Masculine traits of rationality and emotional control drawn on regarding reaction to diagnosis of prostate cancer. Erectile dysfunction impacts on masculine identity
(Gaskin, Andersen, & Morris, 2010)	Australia	Canada	Life History Study	N=1 With Cerebral Palsy	Benefits and costs of compensating for physical disabilities through sports
(Gibson, Young, Upshur, & McKeever, 2007)	Canada	Physical Therapy	Ethnographic Case Study	N=10 living with Duchenne Muscular Dystrophy	Men with DMD were materially, socially, symbolically marginalised through inaccessible physical and social environments.
(Good et al., 2006)	U.S.A.	Psychology	Quantitative measures to assess conformity to gender norms, Gender role conflict. Attitudes towards seeking psychological help, and functional independence	N=33 with TBI and N=19 with SCI	Adhering to traditional masculine values had both positive and negative outcomes for men with TBI and SCI

<u>Reference</u>	<u>Country</u>	<u>Discipline</u>	<u>Design</u>	<u>Sample</u>	<u>Conclusions</u>
(Gorman-Murray, 2008)	Australia	Geography	Critical Review	n/a	Relationships between masculinity and domesticity are impacted by combinations of gender, ethnicity, class and sexuality.
(Gray, Fitch, Fergus, Mykhalovskiy, & Church, 2002)	Canada	Psychosocial Behaviour	Narrative Case Studies	N=3 selected from a group of 18 recruited for a study on prostate cancer	Life prior to illness impacts participants responses post illness. Renegotiating masculine ideals features strongly amongst participants.
(Jones & Curtin, 2010)	Australia	Community Health	Mixed methods Quantitative and Grounded Theory	N=21 Traumatic Brain Injury	Reformulation of gendered identity impacts on satisfaction in taking on household duties in men with traumatic brain injury
(Jonsson, Aus, & Berterö, 2010)	Sweden	Urology	Qualitative hermeneutical interpretation	N=22 men diagnosed with advanced prostate cancer 18-24 months prior to contact	There is a need for knowledge and guidance for men with prostate cancer on how to adjust to new health situation.
(Kilkey & Clarke, 2010)	United Kingdom	Social Sciences	2 Qualitative studies	N= unknown Draws on results of 2 qualitative studies	Disability can have both a constraining as well as opportunistic effect on fathering identities and practices

<u>Reference</u>	<u>Country</u>	<u>Discipline</u>	<u>Design</u>	<u>Sample</u>	<u>Conclusions</u>
(Kvigne, Kirkevold, Martinsen, & Bronken, 2014)	Norway	Nursing	Narrative - Single case study from larger phenomenology study	N=1	Disability impacts on masculinity, Health care providers should be aware of impact gender has on rehabilitation
(Lindemann, 2010)	U.S.A.	Qualitative Research	Ethnography Auto-ethnography Narrative	N=1 and unknown wheelchair rugby participants	Disabled bodies are 'messy' and disabled bodies are asexual, weak, and frail. Identity attached to bodies
(Lindemann & Cherney, 2008)	U.S.A.	Communication	Ethnography	N= 19 players (16 male and 3 female) 2 referees, 4 friends and family members	Wheelchair rugby provides a space for newly quadriplegic persons to learn coping strategies, challenge stigma and validate traditional masculine norms.
(Mfecane, 2012)	South Africa	Anthropology and Sociology	14 Month Ethnographic Study	N=25 HIV positive and using anti-retroviral therapies	HIV disclosure and positive reactions due to a healthy appearance from antiretroviral medications.
(Molyneaux-Smith, Townsend, & Guernsey, 2003)	Canada	Occupational Therapy	Mixed methods	N=47 quantitative survey N=8 qualitative interview Farmers with disabilities	Environmental determinants of farming with a disability were related to social and financial conditions

<u>Reference</u>	<u>Country</u>	<u>Discipline</u>	<u>Design</u>	<u>Sample</u>	<u>Conclusions</u>
(O'Brien, Hunt, & Hart, 2005)	Scotland	Sociology and Public Health	14 focus groups Qualitative	N=55 range of illnesses & injuries	Hegemonic view that men should not seek help from a doctor is endorsed, particularly amongst younger men. Exceptions to the rule exist, such as when help-seeking would <i>preserve</i> or <i>restore</i> a function considered more important on the masculine hierarchy.
(Olfiffe, Ogrodniczuk, Bottorff, Johnson, & Hoyak, 2012)	Canada	Nursing	Grounded theory interviews	N=38	Connecting with family through masculine protector and father roles assists in avoiding suicidal action
(Olfiffe & Phillips, 2008)	Canada	Nursing	Review	n/a	Stigma can be reduced if men are allowed to embrace masculine ideals regardless of not typically fitting them due to depression
(Ostrander, 2008)	U.S.A	Social Work	Grounded Theory	N=11 Violently acquired spinal cord injury (through gunshot injury)	The injury violated the social understandings of what it is to be a man particularly in the areas of sexual encounters, personal safety, body image and choice of intimate partners

<u>Reference</u>	<u>Country</u>	<u>Discipline</u>	<u>Design</u>	<u>Sample</u>	<u>Conclusions</u>
(Park, 2000)	New Zealand	Anthropology	Mixed methods	N=193 postal surveys N=80 face to face interviews People with haemophilia	Individual boys and men developed their own strategies for recreational pursuits. The risk-taking, pain-suppressing values of hegemonic masculinity runs counter to haemophilia treatment best practice
(Rapala & Manderson, 2005)	Australia	Anthropology and Women's Studies	Case Study	N=1 Spinal Cord Injury	Multiple losses relating to adulthood, sexuality masculinity, sport and immigration
(Schopp, Good, Barker, Mazurek, & Hathaway, 2006)	U.S.A.	Psychology and Education	Quantitative measures to assess rehabilitation functional outcome, gender role conflict, traditional masculine role adherence and life satisfaction	N=33 Traumatic Brain Injury	Significant association between masculine role adherence and life satisfaction follow u earnings and FIM change from admission to discharge. Higher conformity to playboy roles correlated with lower life satisfaction
(Schopp, Good, Mazurek, Barker, & Stucky, 2007)	U.S.A.	Psychology and Education	Quantitative measures to assess level of spinal cord injury, rehabilitation functional outcome, gender role conflict, traditional masculine role adherence and life satisfaction	N=20 Spinal cord Injury	Some aspects of traditional male roles can be adapted in a positive manner for rehabilitation while others may become barriers

<u>Reference</u>	<u>Country</u>	<u>Discipline</u>	<u>Design</u>	<u>Sample</u>	<u>Conclusions</u>
(Segal, 2005)	Canada.	Occupational Therapy	Narrative from Grounded theory study	N=1 from a larger study	Changing the nature of tasks and activities that make up an occupation may in turn change the occupation and the personal meaning attached to it
(Shakespeare, 1999)	Britain	Sociology	Range of methods: life history techniques, focussed, unstructured interviews and questionnaires.	N=21 Both heterosexual and homosexual men with a range of disabilities age between 20 and 60 years.	Reformulating masculinity has most positive outcome for men with disabilities. Disabled men can be both victims and oppressors at the same time. Messages of masculinity and disability are contradictory.
(Siu, Seeley, & Wight, 2013)	Uganda	Health	Ethnography	N=26 men(9 HIV positive and receiving anti-retroviral medication, 8 HIV positive not receiving treatment, 6 suspected HIV infection but not tested, 3 with other health concerns unrelated to HIV)	Marriage, children and providing for family important. Along with occupational identity and respect from community. HIV testing and/ or treatment can be a threat to these.
(Stibbe, 2004)	USA	Linguistics	Critical Discourse Analysis	N=6 issues from June-December 2000	Review of USA <i>men's health</i> magazine shows advice given reproduces hegemonic masculine ideals associated with negative health behaviours.

<u>Reference</u>	<u>Country</u>	<u>Discipline</u>	<u>Design</u>	<u>Sample</u>	<u>Conclusions</u>
(Sparkes & Smith, 2002)	England	Sport, Physical Activity and Leisure	Narrative	N=4 Spinal Cord Injury though rugby union	Loss of masculine and, athletic identity as result of SCI. Desire to restore self.
(Taub, Blinde, & Greer, 1999)	U.S.A.	Sociology	Qualitative Content Analysis	N=24	Sport and physical activity may be useful in re-establishing masculine identity after disability
(Tepper, 1999)	U.S.A.	Sexual Health	Auto ethnography	N=1 Spinal Cord Injury	Sexual activity is important part of rehabilitation for men with disability and chronic illness
(Wyrod, 2011)	Uganda	Women's Studies	Ethnography	N=14 (9 Members of Bwaise [HIV] Positive Men's Union, 3 female clinic staff and 1 male, 1 female volunteer)	Men not want to be HIV tested due to: clinics being female spaces, too busy at work, afraid of employment discrimination, relationship break ups and having to deal with consequences of being HIV positive for example loss of independence. Not being able to produce children and provide for family paramount concern.

Appendix C

Letter from University of Canterbury Ethics Committee



HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2012/103

15 August 2012

Donna Ritchie
Health Sciences Centre
UNIVERSITY OF CANTERBURY

Dear Donna

The Human Ethics Committee advises that your research proposal “Men's self-perceptions of masculinity in response to acquired illness and/or injury and subsequent changes in occupational roles” has been considered and approved.

Best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Michael Grimshaw'.

Michael Grimshaw
Chair
University of Canterbury Human Ethics Committee

Appendix D

Counsellor Contact Information Sheet

Health Sciences Centre

Tel: +64 3 364 2987, Fax: +64 3 364 2490
Email: healthsciences@canterbury.ac.nz



COUNSELLOR CONTACT INFORMATION SHEET

Men's self-perceptions of masculinity in response to acquired illness and/or injury and subsequent changes in occupational roles

If you experience any emotional distress as a result of this interview and require additional support, this is a list of some counsellors practicing in the Dunedin Area.

Please note these counsellors are independent providers and are in no way connected to the University of Canterbury or this study. Please be aware there may be a charge involved in visiting some of these services.

Catholic Social Services	477 3403
Family Works	477 7116
Emergency Psychiatric Service (EPS) Dunedin Hospital	474 0999
Lifeline	0800 543 354
Shields Counselling Services	473 6102
Delta Psychology	474 5155
Turning Point	489 6308 ext 721
James Hegarty	473 7090
Trisha Bennett	473 6200
Paul Clymer	467 9055
Elizabeth Gutteridge	471 2284
Michelle Duffy	477 8634

This is not a complete list of service providers in the Dunedin area. More counselling services are listed in the yellow pages phone book under counselling services.

Appendix E

Participant Information Sheet

Health Sciences Centre

Tel: +64 3 364 2987, Fax: + 64 3 364 2490
Email: healthsciences@canterbury.ac.nz

Researcher: Donna Ritchie
Phone: 0800 626 596
Email: donna.ritchie@pg.canterbury.ac.nz



PARTICIPANT INFORMATION SHEET

Men's self-perceptions of masculinity in response to acquired illness and/or injury and subsequent changes in occupational roles

Invitation

If you are a man between the ages of eighteen and sixty-five, living in the greater Dunedin area, who has experienced the ongoing effects of illness or injury over the last six months, then you are invited to participate in a research study looking at what affects, if any, do acquired illness and injury and subsequent changes in occupational roles have on men's self-perceptions of masculinity?

What will I have to do?

You will be asked to participate in one face to face interview with the researcher, at a time and place convenient to you. The interview will take approximately one hour and you will be asked for permission to audio-tape the conversation. You will be given opportunity to review and amend your transcript of the interview. You may also receive one brief follow up phone call or email to clarify any comments that may be unclear as part of the analysis. Your participation is voluntary; you may choose not to answer any questions with which you are uncomfortable and you may withdraw yourself and any data you have provided at any time without having to give a reason. You may also choose to bring a support person with you if you wish.

What questions will I be asked?

You will be asked a range of questions about your life prior to and after experiencing your illness or injury and how this has or has not affected your view of yourself as masculine/ as a man.

Confidentiality

Audio tapes will be transcribed by either the researcher or a professional transcriptionist who will sign an agreement to maintain confidentiality of information. The transcripts will then be analysed by the researcher. Only the researcher and her two supervisors will have access to these data which will be stored in a locked drawer or on a password protected computer. Your name and any personal details you provide will be kept strictly confidential. You will not be personally identified in any publication or presentation of the study.

What will happen to the results of this study?

The findings of this study will be written up in the form of a Master's Thesis and submitted for marking. A copy of this thesis will be lodged in the University of Canterbury Library. Findings may also be published in an academic journal or presented at a conference. You will also receive a summary of the findings if you wish to do so.

What are the benefits and risks of participating in this study?

By participating in this study, you will contribute to the body of knowledge regarding how men experience and cope with illness or injury. It is hoped this information will assist health professionals with improved treatment practices and outcomes for men.

It is acknowledged that talking about your illness or injury may invoke feelings of sadness related to your personal experience. If this does occur you may decline to answer or elaborate on any questions you are uncomfortable with. Information will be provided for how you may receive support if emotional distress occurs.

Who has reviewed this study?

This study has been reviewed and approved by the University of Canterbury Human Ethics Committee.

Who do I contact if I have any questions or concerns about this research?

This study is being carried out as a requirement for a Master's Degree in Health Science (endorsed in Men's Health) by Donna Ritchie under the supervision of Dr Jeffrey Gage and Professor Clare Hocking.

If you have any questions or concerns regarding this study in the first instance please contact:

Donna Ritchie (Researcher)

Phone: 0800 626 596

Email: donna.ritchie@pg.canterbury.ac.nz

If you would prefer to discuss your concerns with someone else then you may contact

Dr Jeffrey Gage (Supervisor)

Phone: 0800 827 7489 ext 7403

Email: Jeffrey.gage@canterbury.ac.nz

OR

The Chair
Human Ethics Committee
University of Canterbury

What do I do now?

If you wish to participate in this study please contact Donna Ritchie by phone or email.

Phone: 0800 626 596

If there is no answer, please leave a clear message on the electronic answering machine with your name and contact details and I will return your call as soon as possible.

Email: donna.ritchie@pg.canterbury.ac.nz

Thank you for your consideration of participation in this study

Yours sincerely

Donna Ritchie

University of Canterbury Private Bag 4800, Christchurch 8020, New Zealand. www.canterbury.ac.nz

Appendix F

Covering Letter to Organisation or Health Practitioner

Health Sciences Centre

Tel: +64 3 364 2987, Fax: + 64 3 364 2490
Email: healthsciences@canterbury.ac.nz

Researcher: Donna Ritchie
Phone: 0800 626 596
Email: donna.ritchie@pg.canterbury.ac.nz



PRACTITIONER REQUEST LETTER

Men's self-perceptions of masculinity in response to acquired illness and/or injury and subsequent changes in occupational roles

15 August 2012

Dear

My name is Donna Ritchie and I am completing a Master of Health Science (endorsed in Men's Health) at the University of Canterbury. As a partial requirement for this degree I am completing a study in the above named area. It is hoped this information will assist health professionals with improved treatment practices and outcomes for men. This study has been reviewed and approved by the University of Canterbury Human Ethics Committee.

I am looking for male participants between the ages of eighteen and sixty-five, living in the greater Dunedin area that are experiencing the ongoing effects of illness or injury over the last six months. I would be very grateful if you would display the recruitment poster in a place visible to potential participants and pass the information sheet on to any men you feel might meet these criteria.

If you have any questions or concerns regarding this study in the first instance please contact:
Donna Ritchie (Researcher)
Phone: 0800 626 596.
Email: donna.ritchie@pg.canterbury.ac.nz

If you would prefer to discuss your concerns with someone else then you may contact

Dr Jeffrey Gage (Supervisor)
Phone: 0800 827 7489 ext 7403
Email: Jeffrey.gage@canterbury.ac.nz
OR

The Chair
Human Ethics Committee
University of Canterbury

Please find enclosed a copy of the ethical approval for this study, recruitment poster and information sheets for participants.

Kind Regards

Donna Ritchie

University of Canterbury Private Bag 4800, Christchurch 8020, New Zealand. www.canterbury.ac.nz

Appendix G

List of Health Practitioners and Organisations Contacted

Jeni Blezard – Clinical Psychologist

Dr. Mike Anderson – Pain Specialist

Dr. Blair McLaren – Medical Oncologist

Dr. John North – Radiation Oncologist

Prof. John McCall – General Surgeon

Prof. Rob Walker – Renal Specialist

Dr. Dick Bunton – Chief Medical Officer Southern DHB

Dr. Vic DuPlessis – Neurological Specialist

Dunedin Hospital

North and South Community Psychiatric Teams

Community Rehabilitation Team Wakari Hospital

Miramare - Needs Assessment

Rata South – Rehabilitation Service

Mornington PHO

PACT Group – Mental health service

Respiratory, Rheumatology and Cardiology Outpatient Services – Southern DHB

Appendix H

Poster



- **ARE YOU A MAN BETWEEN THE AGES OF 18 AND 65?**
- **DO YOU EXPERIENCE THE ONGOING EFFECTS OF INJURY OR ILLNESS?**
- **DO YOU LIVE IN THE GREATER DUNEDIN AREA?**
- **DO YOU HAVE A SPARE HOUR TO TALK ABOUT YOUR EXPERIENCES?**

If you have answered yes to the above questions then I would like to talk to you.

For further information please contact

Donna Ritchie

Phone: 0800 626 596

Email: donna.ritchie@pg.canterbury.ac.nz

Donna Ritchie 0800 626 596 Donna.ritchie@pg.canterbury.ac.nz	Donna Ritchie 0800 626 596 Donna.ritchie@pg.canterbury.ac.nz	Donna Ritchie 0800 626 596 Donna.ritchie@pg.canterbury.ac.nz	Donna Ritchie 0800 626 596 Donna.ritchie@pg.canterbury.ac.nz	Donna Ritchie 0800 626 596 Donna.ritchie@pg.canterbury.ac.nz	Donna Ritchie 0800 626 596 Donna.ritchie@pg.canterbury.ac.nz	Donna Ritchie 0800 626 596 Donna.ritchie@pg.canterbury.ac.nz	Donna Ritchie 0800 626 596 Donna.ritchie@pg.canterbury.ac.nz	Donna Ritchie 0800 626 596 Donna.ritchie@pg.canterbury.ac.nz	Donna Ritchie 0800 626 596 Donna.ritchie@pg.canterbury.ac.nz
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Appendix I

Covering Letter for Participants

Health Sciences Centre

Tel: +64 3 364 2987, Fax: + 64 3 364 2490
Email: healthsciences@canterbury.ac.nz



PARTICIPANT RESPONSE FORM

Men's self-perceptions of masculinity in response to acquired illness and/or injury and subsequent changes in occupational roles

Date

Dear

Thank you for your interest in the above named study. Please find enclosed the information sheet for participants. I will contact you in a few days to see if you are still interested in taking part in this study.

If you have any further questions in the meantime please feel free to contact myself on 0800 626 596 or email. donna.ritchie@pg.canterbury.ac.nz.

Kind Regards

Donna Ritchie

Appendix J

Informed Consent Form

Health Sciences Centre

Tel: +64 3 364 2987, Fax: +64 3 364 2490
Email: healthsciences@canterbury.ac.nz

Researcher: Donna Ritchie
Phone: 0800 626 596
Email: donna.ritchie@cc.canterbury.ac.nz



CONSENT FORM

Men's self-perceptions of masculinity in response to acquired illness and/or injury and subsequent changes in occupational roles

- I have read and understood the information sheet for the above-named study.
YES/NO
- I understand that the interview will be audio recorded
YES/NO
- I understand what this research is about and my questions have been answered.
YES/NO
- I understand this study has been reviewed and approved by the University of Canterbury Human Ethics committee.
YES/NO
- I understand that taking part in this study is voluntary and that I may withdraw from the study, including withdrawal of any data I have provided, at any time and for any reason.
YES/NO
- I consent to the publication of the results of the study with the understanding that anonymity will be preserved.
YES/NO
- I know who to contact if I have any questions or concerns about this study.
YES/NO
- I have had time to consider whether to take part.
YES/NO
- I wish to receive a summary of findings.
YES/NO
- I consent to participate in this study.
YES/NO

FULL NAME: (please print).....

SIGNATURE:

DATE:

ADDRESS:

PHONE:

EMAIL:

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Appendix K

Interview Guide

Demographic Data:

age, ethnicity, type of illness or injury and the length of time they have been living with it.

Tell me what life was like for you prior to your accident (or illness).

What did being masculine mean to you then?

What kind of things did you do?

In your family life? Time with children, partner, jobs around the home...

Work life – Were you employed? What did you do? Did you work full time?

What did you do in your social life? With your friends?

What hobbies/ sports were you involved in?

Tell me about your injury/ illness

What was it like for you?

How did this affect your life?

How did things change for you?

In your family life? Time with children, partner, jobs around the home...

Work life – employment? What do you do now?

What do you do in your social life? With your friends?

What hobbies/ sports are you involved in?

How did this affect your view of yourself as masculine/ as a man?

Is there anything that we haven't talked about that you would like to add?

Appendix L

Transcriber Confidentiality Form

Health Sciences Centre

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Email: healthsciences@canterbury.ac.nz

Researcher: Donna Ritchie
Phone: 0800 626 596
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TRANSCRIBER CONFIDENTIALITY FORM

Men's self-perceptions of masculinity in response to acquired illness and/or injury and subsequent changes in occupational roles.

- I understand that I will be hearing and transcribing data for the above named study.
- I agree to maintain confidentiality of these data and not reveal its contents to anyone other than the researcher.
- I will delete all files on my computer once transcription is complete and will not keep any electronic or hard copies of the data.

FULL NAME: (please print).....

SIGNATURE:

DATE:

This study has received ethical approval from the Human Ethics Committee, University of Canterbury.

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